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# Working with chronic illness: The application of health psychology in Renal and Liver transplant services

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2/1/2017

Portfolio submitted in fulfilment of the requirements for the degree of Doctor of Health Psychology, Department of Health Sciences, City University London

## CONTENTS PAGE

### Table of Contents

CONTENTS PAGE .....	1
Table and Figures Contents.....	9
Acknowledgments.....	10
Declaration .....	12
SECTION A: PREFACE .....	13
Preface.....	14
Work Context – Assistant Clinical Health Psychologist.....	14
End Stage Renal Disease.....	15
Adherence .....	15
Psychological Distress .....	16
Liver transplantation .....	17
Adjustment and Quality of Life following Liver Transplantation.....	18
Summary .....	18
References .....	19
SECTION B: RESEARCH .....	23
ABSTRACT .....	24
CHAPTER ONE: INTRODUCTION TO THE QUALITY OF LIFE OF PEOPLE RECEIVING LIVER TRANSPLANTS .....	26
1.0 INTRODUCTION .....	26
1.1 Background to Liver Transplantation .....	26
1.2 Health related quality of life .....	26
1.3 Psychosocial Vulnerabilities .....	28
1.4 Pediatric Liver Transplant.....	30
1.5 Adult liver transplant – review of the literature.....	31
1.6 Liver transplant studies in the nursing literature.....	32
CHAPTER 2: A GROUNDED THEORY EXPLORATION OF ADAPTATION FOLLOWING LIVER TRANSPLANT .....	35
2.0 METHODOLOGICAL APPROACH.....	35
2.1 Epistemological Perspective .....	35
2.1.1 The Role of Theory:.....	35
2.1.2 Realism versus Relativism:.....	36
2.1.3 Politics:.....	36
2.2 Constructivist and Objectivist Grounded Theory .....	37

2.3 Grounded theory as an evolving process .....	38
2.4 Grounded Theory through a Psychosocial lens.....	42
2.5 Using Computer-Assisted Qualitative Data Analysis Software (CAQDAS) to facilitate the grounded theory analysis process.....	43
2.5.1 Closeness and distance:.....	43
2.5.2 Code and retrieve methods:.....	44
2.5.3 Mechanisation of analysis:.....	45
2.6 Sample, Eligibility and Recruitment .....	47
2.6.1 Sample:.....	47
2.6.2 Eligibility: .....	47
2.6.3 Recruitment:.....	48
2.6.4 NHS recruitment: .....	49
2.6.5 Online recruitment: .....	49
2.6.6 Theoretical Sampling:.....	50
2.6.7 Saturation: .....	51
2.6.8 Interview Procedure: .....	52
2.6.9 Data analysis: .....	53
CHAPTER 3: DEVELOPING AN EXPLANATORY THEORY FOR THE ADAPTATION PROCESS.....	55
3.0 INTRODUCTION TO FINDINGS .....	55
CHAPTER 4: EXPLORING THE PHENOMENON OF HAVING A LIVER TRANSPLANT: THE TRANSPLANT JOURNEY.....	57
4.0 THE TRANSPLANT JOURNEY.....	57
4.1 Diagnosis.....	57
4.2 Pre-Transplant.....	63
4.3 Transplant.....	65
4.3.1 <i>Table: Participant discharge time frame</i> .....	76
4.4 Post-transplant.....	77
CHAPTER 5: EMERGING PROTECTIVE FACTORS.....	86
5.0 PROTECTIVE FACTORS .....	86
5.1 Realistic Optimism.....	86
5.2 Facing fear.....	89
5.3 Receiving a gift, altruism and giving back.....	92
5.4 Religion and Spirituality .....	97
5.5 Social Support and Networks.....	100
5.5.1 <i>Table: Types of support</i> .....	106
5.6 Role Models and Learning.....	107
5.7 Physical Fitness and Strengthening in Recovery .....	108

5.8 Brain fitness .....	111
5.9 Cognitive and Emotional Flexibility .....	116
5.10 Making meaning, purpose and growth.....	119
5.11 Meaning making through storytelling.....	120
5.12 Posttraumatic growth .....	122
5.12.1 Table: Types of Post-traumatic growth.....	127
CHAPTER 6: RESILIENCE AND GROWTH THROUGH DISRUPTION.....	129
6.0 RESILIENCE AND GROWTH.....	129
6.1 Limitations, Clinical Implications and Further Research .....	134
6.3 Conclusion .....	136
References .....	138
SECTION B: APPENDICES.....	162
APPENDICES: SECTION B RESEARCH.....	163
Appendix 1: Recruitment Documentation .....	164
Appendix 2: Initial Interview Schedule .....	171
PUBLISHABLE ARTICLES .....	174
Title: Supporting Patients Better on Self-Care Haemodialysis.....	175
Summary: .....	175
Background: .....	175
Aim: .....	175
Method: .....	175
KEYWORDS: .....	175
Introduction .....	176
Barriers:.....	176
Education: .....	177
Self-cannulation: .....	178
Procedures of Supporting and Training Self-Care Dialysis:.....	179
Method .....	179
Definitions:.....	179
Inclusion/Exclusion:.....	179
Main Questions: .....	180
Results .....	180
General Questions about self-care: .....	180
Experiences of current Support:.....	181
Experiences of learning supportive self-care dialysis:.....	182
Discussion .....	183
General questions about self-care .....	184

Experiences of current support.....	184
Experiences of learning supportive self-care .....	184
Nurses: .....	185
Patients own Resources:.....	185
Peer and Family Support:.....	186
Key point sentences.....	187
References .....	189
Supporting Patients Better on Self-Care Haemodialysis: Illustrations and Figures ....	195
Figure 5: Suggested recommendations for self-care haemodialysis services to consider	
Title: Self-Cannulation – Exploring the Process.....	199
Abstract .....	200
Introduction .....	200
Arterial Vascular Fistula’s (AVF’s).....	201
AVF self-care:.....	202
Deciding to try self-care haemodialysis and self-cannulation .....	203
Needle Phobia .....	206
Pain and anticipation pain .....	207
Patient Experience.....	209
Conclusion .....	210
References .....	212
<b>SECTION C: PROFESSIONAL PRACTICE .....</b>	<b>220</b>
<b>CORE UNIT 1: GENERIC PROFESSIONAL COMPETENCE.....</b>	<b>221</b>
Unit 1.1 Implement and maintain systems for legal, ethical and professional standards in applied psychology .....	221
Unit 1.2 Contribute to the continuing development of self as a professional applied psychologist .....	223
Unit 1.3 Provide psychological advice and guidance to others .....	226
Unit 1.4 Provide feedback to clients .....	228
Reflection .....	229
References .....	230
<b>CORE UNIT 3 CONSULTANCY COMPETENCE.....</b>	<b>231</b>
<b>Core Unit 3 – Consultancy Case Study.....</b>	<b>231</b>
Background .....	231
Context .....	231
3.1 Assessment of request for consultancy .....	232
3.2 Plan consultancy.....	234
3.3 Establish, develop and maintain working relationships with clients .....	236
Contracts and Budgets.....	237

3.4 Conduct consultancy .....	237
3.5 Monitor the implementation of consultancy .....	239
Initial Findings .....	239
3.6 Evaluate the impact of consultancy.....	240
References .....	242
<b>CORE UNIT 4 TEACHING AND TRAINING COMPETENCE .....</b>	<b>244</b>
Core Unit 4 - Teaching and Training .....	244
Lectures in Health Promotion – MSc Health Psychology Programme.....	244
Background .....	244
Context .....	244
4.1 Plan and design training programmes that enable students to learn about psychological knowledge, skills, and practices.....	245
Assess Training Needs .....	245
Literature Review .....	245
Identify training programme structures and content .....	246
4.2 Deliver such training programmes .....	247
Implementing training methods and delivering the programmes .....	247
4.3 Plan and implement assessment procedures for such training programmes .....	249
4.4 Evaluate such training programmes .....	249
References .....	251
Teaching Programmes in a Health Care Setting .....	254
Background .....	254
Context .....	254
4.1 Plan and design training programmes that enable students to learn about psychological knowledge, skills, and practices.....	255
Assess Training Needs .....	255
Literature Review .....	255
Identify training programme structures and content .....	256
4.2 Deliver such training programmes .....	257
Implement training methods .....	257
4.3 Plan and implement assessment procedures for such training programmes .....	259
4.4 Evaluate such training programmes .....	260
References .....	261
<b>CORE UNIT 5 IMPLEMENT INTERVENTIONS TO CHANGE HEALTH- RELATED BEHAVIOUR .....</b>	<b>263</b>
Core Unit 5 – Behaviour Change Case Study .....	263
Implement interventions to change health-related behaviour .....	263
Service Background .....	263



Overview of Chronic Kidney Disease.....	263
5.1.a Assessing the suitability of client for health-related behaviour intervention...	265
Background information to case .....	265
Initial Assessment .....	265
Literature Review and Formulation .....	266
5.1b Identify and negotiate the behaviour change goals of the client.....	268
Defining Goals .....	268
5.1c Assess the cognitive, behavioural and situational determinants of relevant current behaviour .....	270
Session 2 - 4 .....	271
5.1d Develop a behaviour change plan based on cognitive-behavioural principles .	272
5.1e Ensure monitoring and support for behaviour change plan .....	273
5.1f Evaluate outcome.....	274
5.1g Negotiate completion, follow-up or referral as appropriate.....	274
References .....	276
<b>CORE UNIT 6.3 COMMUNICATE PROCESS AND OUTCOMES OF INTERVENTION OR CONSULTANCY .....</b>	<b>278</b>
Core Unit 6 – Case Study .....	278
Background .....	278
Context .....	279
The European Dialysis and Transplant Nurses Association/European Renal Care Association:.....	279
6.3a Prepare information for dissemination .....	280
Abstract .....	280
6.3b Present information to individuals, groups and organisations on the processes and outcomes of psychological interventions, consultancies.....	282
6.3c Evaluate the impact of disseminated information .....	283
References .....	285
<b>SECTION C: APPENDICES.....</b>	<b>286</b>
<b>APPENDICES: CORE UNIT 3 .....</b>	<b>287</b>
<b>CONSULTANCY .....</b>	<b>287</b>
Appendix 1: Project Proposal.....	288
Appendix 2: Contract and Budget.....	291
Appendix 3: Information Leaflet .....	292
Appendix 4: Workshop slides - Session 1 .....	293
Session 2 .....	299
Appendix 5: Workshop Summary Booklets – Session 1 .....	305
Session 2.....	319

Appendix 6: Pre and Post Patient Questionnaires.....	342
Appendix 7: Meetings.....	359
APPENDICES: CORE UNIT 4.....	363
TEACHING AND TRAINING.....	363
MSc HEALTH PSYCHOLOGY PROGRAMME.....	364
Appendix 1: MSc Health Promotion Teaching Plan.....	364
Appendix 2: Handouts.....	369
Lecture 1.....	369
Lecture 2.....	376
Appendix 3: Feedback Form.....	385
Appendix 4: Feedback results.....	386
Reflective commentary of MSc Health Promotion Lecture.....	388
Body Language – Moving about too much.....	388
Teaching Styles and Tools.....	388
Quiz:.....	388
Integrating competition:.....	389
Pace:.....	389
Personal experiences:.....	389
References.....	390
Teaching and Training Observer Report.....	391
TEACHING PROGRAMMES IN HEALTH CARE SETTINGS.....	392
Appendix 1: Motivational Interviewing Teaching Plan.....	392
Appendix 2: Additional Hand Outs Used.....	394
Appendix 3: Evaluation Form.....	404
APPENDICES: CORE UNIT 5.....	407
Behaviour Change.....	407
Appendix 1: Referral guidelines.....	408
Appendix 2: Referral Algorithm.....	409
Appendix 3: Patient information leaflet.....	410
Appendix 4: Stepped Care Model.....	411
Appendix 5: Stages of CKD.....	412
Appendix 6: Summary of guided CBT.....	413
Appendix 7: Summary and Use of Brief Solution Focused Therapy.....	414
Appendix 8: Referral Form.....	416
Appendix 9: Hospital Anxiety and Depression Scale.....	417
APPENDICES: CORE UNIT 6.3.....	418

COMMUNICATE PROCESS AND OUTCOMES OF INTERVENTION OR CONSULTANCY .....	418
Appendix 1: Mind and Body Matters Abstract .....	419
Solihull. 6/7th November 2011 .....	419
Appendix 2: Conference Programme.....	421
Appendix 3: EDTNA/ERCA Mind and Body Matters in Renal Care Presentation	424
SECTION D: SYSTEMATIC REVIEW .....	427
Quality of life after liver transplantation: An updated systematic review .....	428
Introduction .....	428
Quality of Life:.....	428
Generic vs Specific Quality of Life Measures: .....	429
Cross sectional vs Longitudinal Studies: .....	431
Objectives:.....	432
Materials and Methods .....	432
Ethical and Other Restrictions: .....	433
Search Strategy: .....	434
Search Terms:.....	435
Assessing Risk of Bias:.....	435
Seven areas were assessed for risk of bias including:.....	435
Results .....	436
Study selection: .....	436
Study characteristics: .....	439
Domain findings:.....	439
Assessing risk of bias:.....	448
Discussion .....	453
References .....	454
SECTION D: APPENDICES.....	460
APPENDICES: SYSTEMATIC REVIEW .....	461
Appendix 1: Study Eligibility Form.....	462
Appendix 2: Assessment of Bias Tool .....	466

## Table and Figures Contents

### SECTION B: RESEARCH

2.3.1. Table: Key Grounded Theory Characteristics.....	40
4.1.1. Table: Known causes of End Stage Liver Disease Transplantation as Treatment....	60
4.3.1. Table: Participant discharge time frame.....	74
5.5.1. Table: Types of Support.....	102
5.12.1. Table: Types of Post-Traumatic Growth.....	124
6.0.1. Table: Three Waves of Resiliency Inquiry.....	130
6.0.2. Figure 1: Resiliency Model.....	131
6.0.3. Figure 2: Process of adaptation following a Liver Transplant.....	133

### SECTION B: SUPPORTING PATIENTS BETTER ON SELF-CARE HAEMODIALYSIS: ILLUSTRATIONS AND FIGURES

Figure 1: Skills Assessment Sheet.....	195
Figure 2: Overall duration on haemodialysis as a predictor of starting SCD.....	195
Table 1: General Questions about self-care haemodialysis Questions 1b, 2 and 3.....	196
Figure 3: Do you feel you receive enough support from specialist nurses.....	196
Table 3: What helped you the most when learning how to self-care on haemodialysis....	197
Figure 4: Some people can have problems with specific areas such as preparing access and learning how to do needling, what did you find most challenging.....	198
Figure 5: Suggested recommendations for self-care haemodialysis services to consider..	199

### SECTION C: UNIT 3 CONSULTANCY COMPETENCE

3.2.1. Figure 1: Identifies three main components addressed whilst planning the consultancy .....	234
---	-----

### SECTION C: UNIT 4 TEACHING AND TRAINING COMPETENCE

4.2.1. Table 1: Activities that accommodate Kolb learning process.....	248
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### SECTION C: UNIT 5 BEHAVIOUR CHANGE

5.1c. Figure 1: Formulation.....	272
5.1f. Figure 2: HADS Outcome.....	274

### SECTION D: SYSTEMATIC REVIEW

Table 1: Inclusion and Exclusion criteria using PICOs.....	433
Table 2: Reasons for exclusion.....	437
Figure 1: Flow chart summary of database search.....	438
Table 3: Characteristics of search included studies.....	440
Table 4: SF36 domain findings.....	444
Table 5: Assessment Bias – Before and After Studies.....	449
Table 6: Assessment of Bias – Cross sectional studies.....	451

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"Around here, however, we don't look backwards for very long. We keep moving forward, opening up new doors and doing new things...and curiosity keeps leading us down new paths." – Walt Disney

This thesis is dedicated to Julie Wong and James Wong  
for their never ending love and sacrifice.

## **Declaration**

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# **SECTION A: PREFACE**

## Preface

This thesis and portfolio documents evidence of attaining competencies in research, teaching and training, consultancy, behaviour change intervention and communicating processes and outcomes of a consultancy as part of a Doctorate in Health Psychology. Practical elements of this portfolio were completed on employment as an Assistant Clinical Health Psychologist within the NHS as part of the Renal and Liver Transplant Clinical Health Psychology Service.

### **Work Context – Assistant Clinical Health Psychologist**

The placement role as an Assistant Clinical Health Psychologist focused on the psychological and mental health problems relating to chronic illnesses, particularly End Stage Renal Disease (ESRD) and End Stage Liver Disease resulting in transplantation. In the last 50-60 years treatment has developed for both Renal and Liver, thus lengthening the lives of a wealth of individuals. Psychological difficulties such as adherence and mood disorders have increasingly been identified in clinical settings and health research; increasing the awareness and the importance of psychological care from diagnosis through treatment and end of life care and with a growing importance of patient quality of life.

The role of an Assistant Psychologist is supportive of a fully qualified psychologist; in this case a Consultant Clinical Psychologist and a Principle Health Psychologist. Based within a multidisciplinary team of clinicians in a hospital, this particular position was primarily employed as a clinician providing brief level individual therapies. In combination with the training on the Doctorate of Health Psychology the Assistant Psychologist was able to further apply skills under the supervision of qualified psychologists in areas of research, consultancy, teaching/training and dissemination of research. The additional training and application of skills enabled the development of the wider Renal and Liver services and ability to support and project lead in areas of research, providing psychological evidence based consultation.

## End Stage Renal Disease

End Stage Renal Disease is unique in many ways amongst other medical conditions due to the development of treatments that cause patient dependence on artificial means for survival. Despite its uniqueness ESRD shares many of the core psychological difficulties seen in other chronic medical conditions (Christensen & Ehlers, 2002). Some of these core psychological problems are addressed within the following competencies and case studies in this portfolio.

## Adherence

Implications of adherence to treatment regimens such as prescribed medication and/or Renal Replacement Therapies (RRT) Christensen & Ehlers (2002) suggest are the most important behavioural influence on ESRD patient outcomes. For example, patients are required to maintain strict fluid and dietary restrictions whilst on haemodialysis; fluid overload can result in symptoms such as hypertension, pulmonary oedema, or even lower patient survival and congestive heart failure. Dietary requirements with medication include the use of phosphate binding medication along with a reduction of phosphate and potassium rich foods. Non-adherence to medication and dietary requirements can result in multiple complications (renal osteodystrophy; bone demineralisation; life-threatening cardiac arrhythmia). Non-adherence issues are also problematic following organ transplant; irregular intake or not taking immunosuppressant medication can lead to organ rejection or increased risk of infection (Armstrong & Weiner, 1982; De Geest et al 1995).

Much of the everyday placement work (Section C: Core Unit 1) in the Low Clearance and transplant multidisciplinary team (MDT) meetings, psychology Low Clearance and transplant clinics were related to early identification of the potential challenges of adherence; for both health care professionals and patients. In fact, almost every competency touched on an issue relating to adherence. Where regular therapeutic practice in Section C: Core Unit 1

saw referrals routinely requiring treatment adherence, Section C: Units 3, 4 and 5 supported early self-management for patients (Section C: Unit 3); introduction to motivational interviewing, informal consultancy with clinicians to support skills to improve management of adherence and academic lectures introducing health promotion and intervention (Section C: Unit 4); and individual therapeutic behaviour change work informed by Cognitive Behavioural Therapy (Section C: Unit 5). The range of intervention work varying from individual patient work to supporting staff through consultancy and early psychoeducational groups for patients within this portfolio, highlights the possibilities for addressing adherence at a number of levels and the importance of fully understanding and formulating the problem before upskilling both patient and clinician. Section C: Unit 3 provided data from a pilot group on the usefulness of psychoeducation groups for introducing self-management concepts to patients. Its success prompted further interest and dissemination of the result within the EDTNA/ERCA conference (Section C: Unit 6.3).

## **Psychological Distress**

Kimmel, Thamer, Richard & Ray (1998) suggest the rate of psychiatric disorders in ESRD is substantially higher in comparison with other chronic illnesses. Most commonly reported were mood disorders, dementia and substance use disorders (Kimmel, Thamer, Richard & Ray, 1998), with some studies also linking depression with non-adherence in ESRD (Chilcot et al, 2010; Khalil, Lennie, & Frazier, 2010; Cukor, Rosenthal, Jindal, Brown, & Kimmel, 2009). Several studies propose that the prevalence of depression in patients with ESRD is between 12-40% (Craven, Rodin & Johnson, 1987; Craven Rodin & Littlefield, 1989; Hinrichsen, Lieberman, Pollack & Sternberg, 1989). Despite no specific guidance for treatment for depression in ESRD, there is a recognized need for psychological support for people with established renal failure (Rabindranath, Daly, Butler, Roderick, Wallace, Macleod, 2009). Additionally, highlighting the shared problem of depression throughout chronic illnesses, NICE

(2009) released guidance specific for 'Depression in Adults with a Chronic Physical Health Problem'. Thus a common theme running alongside adherence within this portfolio is the management of distress.

Due to increasing diagnoses of mood disorders within the Renal service, individual interventions for mood disorders were routinely referred (Section C: Unit 1). Section C: Unit 5 details a more specific case, demonstrating the management of distress directly with a patient, where assessment enabled formulation of the problem of adherence and hypothesized it's maintenance through anxiety and depression. Whereas, Section C: Unit 3 attempts to address distress from an early intervention approach; the second session of the psychoeducational group carried out, specifically targets management of stress and coping strategies. Furthermore, Low clearance clinicians requested for teaching on adjustment in chronic kidney disease with the aim of better identifying when distress is 'normal' and when to refer for psychological intervention for mood disorders (Section C: Unit 4). This highlights a need for supporting the professional development and knowledge of clinicians in both the identification of psychological illnesses and how best health care professionals can support patients with psychological difficulties.

## **Liver transplantation**

Development in effective immunosuppressive treatment and surgical techniques has enabled organ transplantation to become routine clinical practice and psychological evaluation of transplant candidates is widely endorsed (Debray & Plaisant, 1990; Dew, Switzer et al, 2000; Dobbels et al, 2001; Levenson & Olbrisch, 1993; Streisand et al, 1999). Work with transplant candidates during placement spanned across both Renal and Liver Services (Psychological Services for Liver were limited to transplant patients due to lack of resources and funding). Goals of the Psychology Transplant clinics held (Section C: Unit 1) were to identify potential risk factors that may result in post-transplant complications, non-adherence and morbidity

(Shapiro et al, 1995; Bryant & Reams, 1997) and ensure transplant candidates were well informed for treatment planning (Dew, Switzer et al, 2000). Due to medical advances, prolonged survival is now accepted however longer term effects on the cognitive and psychological outcome are unclear (O'Carroll, Couston, Cossar, Masterton & Hayes, 2003). Thus quality of life (QOL) and adapting following transplantation has become a growing area of importance. The focus on QOL, and what enables individuals to live positively following a life altering procedure like having a liver transplant is the main area of research in Section B: Unit 2 and Section D: Unit 2.

### **Adjustment and Quality of Life following Liver Transplantation**

Liver transplant survival rate is considered highly satisfactory (Blanch et al, 2004) thus more recent research has turned to QOL and psychosocial functioning. Indeed, two previous systematic reviews investigating QOL following liver transplant have been carried out prior to the systematic review in Section D (Bravata, Olkin, Barnato, Keeffe & Owens 1999; Tome, Wells, Said & Lucey, 2008) however as medicine and surgical techniques advance, so must the measurement and focus on improving quality of life. Thus Section D: Systematic Review emphasises the assessment of the quality of the measurements and whether specific or generic measures have been used since the development of specific measures. From the establishment that liver transplantation is effective in improving quality of life in majority of cases (see Section D: Systematic Review), Section B: Research goes on to explore how post-liver transplant patients adjust and how the transplantation journey transforms them post-transplant.

### **Summary**

The overall portfolio is a demonstration of how health psychology theory can be applied directly within medical contexts, working alongside a range of health care professionals. Despite case studies specifically relating to ESRD and Liver transplant

psychological problems such as adherence, mood disorders and quality of life, span across all chronic illness settings. Case studies and research demonstrate the potential range of health psychology theory that can be applied to direct patient work (individual and group) and health practitioners. Research focusing on adaptation following transplantation supports the development in areas of Positive Psychology (Seligman, 2014) and Resilience (Reich, Zautra, Hall, 2010) for better quality of life.

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# **SECTION B: RESEARCH**

## ABSTRACT

Background: Liver disease is one of the top ten causes of death in the U.K . With an increase of 12% between 2005-2008 (British Liver Trust, 2008), liver transplantation has become the treatment of choice for liver disease. Due to improved effectiveness of medication and advancement of surgical techniques, clinical outcomes for liver transplant have continued to improve. Focus has turned to quality of life and how effectively a patient post-transplant can return to routines of daily living (Rainer, Thompson & Lammbros, 2010).

A small number of qualitative studies have explored the experiences of adults following liver transplantation in the nursing literature. Studies previously carried out have mainly emphasised physical and medical issues such as adherence, side effects, infection, death and dying. Whereas other research has emphasised the transplant recipients' functionality and ability to perform everyday tasks and fulfil social roles. Past investigations into liver transplant have been measured by the absence of medical complaints, however, questioning how individuals struggle do not always reflect how patients who have experienced a transplant have adapted throughout the recovery period.

Aims: The present study aims to explore the experience of patients who have experienced a liver transplant and how they have adapted throughout the recovery period. The study intends to develop a theoretical model which can inform targeted psychological treatment to encourage and optimise patient recovery following transplantation.

Methodology: Data was collected via semi-structured one to one interviews, from a sample of liver transplant recipients via routine follow-up clinics. A modified grounded theory approach (Corbin & Strauss, 1998) was used as the main method of gathering synthesizing and

conceptualising the data, supported by the use of Computer-Assisted Qualitative Data Analysis Software (CAQDAS) to facilitate the grounded theory process.

Findings: A total of 11 transplant recipients consented to be interviewed providing a unique insight into the experiences of liver transplant and post-surgical recovery. Findings are explored in stages; 1. Exploring the phenomenon of having a liver transplant; 2. Protective Factors; and finally, 3. The core concept of Resilience. Findings indicated a number of concepts, demonstrating the journey for liver transplant recipients from diagnosis through to the ongoing recovery period. Participants demonstrated multiple strengths and protective coping mechanisms helping them through each phase of 'disruption' and the use of narrative to re-organise, formulate and make meaning of their experiences. Data collected through interviews provided overwhelming evidence for protective factors rooted within the core concept of resilience.

Conclusion: Evidence from the study and current research on resilience suggests that future interventions may need to focus less on risk amelioration and instead develop resources to enhance protective coping early on, impacting future resiliency.

# **CHAPTER ONE: INTRODUCTION TO THE QUALITY OF LIFE OF PEOPLE RECEIVING LIVER TRANSPLANTS**

## **1.0 INTRODUCTION**

### **1.1 Background to Liver Transplantation**

In the last several years Liver Transplantation has developed as the treatment of choice for end stage liver disease, caused by a variety of disorders (Bravata, Olkin, Barnato, Keefe and Owens, 1999). Improved effectiveness of immunosuppressant therapies has enabled advancement of surgical techniques from laboratory to clinical practice (Starzl, 1996). In 2002, the United States was performing approximately 4,500 liver transplants per year (United Network for Organ Sharing [UNOS], 2001).

Liver transplant is performed for a wide range of illnesses, however, most commonly for decompensated cirrhosis secondary to chronic viral hepatitis or alcohol abuse, (Olbrisch, Benedict, Asche and Levenson, 2002). Analysis of the official statistics by the British Liver Trust (2008) highlights that liver disease is the only major cause of death that continues to increase every year (Office for National Statistics, 2008). Liver disease is the fifth 'big killer' in England and Wales with deaths in liver disease having increased by 12% in three years (2005-2008) (British Liver Trust, 2008). Patients with end-stage liver disease can experience a variety of symptoms that can impact their quality of life and physical functioning, including fatigue, encephalopathy, mild sleep disturbance, delirium or even coma.

### **1.2 Health related quality of life**

Clinical outcomes for liver transplant continue to improve with increased 1 year survival rates for adult recipients to 80%-90% (Seaberg, Belle, Beringer, Schivins & Detre,

1997), fewer postoperative complications and more effective immunosuppression (Bravata, Olkin, Barnato, Keefe & Owens, 1999). Thus other outcomes such as health related quality of life (HRQL) and employment become increasingly important targets for evaluation. Investigations into psychosocial issues among organ transplant candidates has tended to reflect a more quantitative tradition of medicine, i.e. primarily on this medical definition of the quality of life construct and how effectively an individual returns to their routines of daily living and return to work (Rainer, Thompson and Lambros, 2010). However, health related quality of life is an important measurement because patients tend to be more concerned about quality of life than longevity (Gage, Cardinalli and Owens, 1996; McNeil, Weichselbaum and Puker, 1981). Additionally with ongoing side effects and debilitating physical functioning HRQL can provide a more complete analysis of overall health status (Younossi and Guyatt, 1998). Lepage and Hunt (1997) highlight that in the medical literature little legitimacy is given to the patient's subjective perspective or seen as valid. Instead the biological perspective is primarily focused on instead and thus the patients' actual psychological needs can be lost in the process. In further consideration of the cost and lack of resources involved in liver transplant, full health-economic analyses including HRQL is also key for evaluation of cost-effectiveness and general effectiveness of liver transplantation.

In a meta-analysis of quality of life after liver transplantation Bravata, Olkin, Barnato, Keefe and Owens (1999) showed that the most significant improvements post-transplant were in physical health, sexual functioning, daily activities and general quality of life. Where this improvement in physical related functioning and of daily activities is somewhat expected and hoped for, they also acknowledged that the psychosocial aspects of quality of life showed the smallest improvements post-transplant (including psychological and social functioning). They suggest that these could be attributed to retrospective data collection where longer periods of time had passed between transplantation and data collection, thus the passing of the initial excitement after having received a transplant (Moore, Jones, Angus, Hardy and Burrows, 1992;

House, Dubovsky and Penn, 1983). Other studies have suggested the persistent psychological impairment post-transplant to be due to incomplete recovery from neurophysiological damage caused by pre-transplant liver disease (Tarter, Van Theil, Hegedus, Schade, Gavaler and Starzl, 1984; Hockerstedt, Kajaste and Isoniemi, 1990; Bernthal, Hays and Tarter, Van Thiel, Lecky, & Hegedus, 1987).

Where considerable HRQL improvement was found in Bravata et al's (1999) study described above, a subset of transplant recipients did not experience improvement. Bravata et al suggests that knowledge of these factors related to decreased HRQL following liver transplant would enable development of new intervention strategies and potentially affect the future decisions of allocation of organs (Goff, Glazner and Bilir, 1998). Bravata et al further recommend that transplantation treatment programmes expand the area of psychological and social support available to patients. Therefore in line with these recommendations, the current study intends to investigate how patients who have experienced a liver transplant adapt to daily living after their transplant. Through a qualitative approach interviewing a subset of liver transplant patients, common areas of challenges and abilities to adapt may help to inform psychological and social support provision to liver transplant patients.

### **1.3 Psychosocial Vulnerabilities**

Baines and Jindal (2003) acknowledged that the emotional and psychological manifestations in patients receiving organ transplants have been recognised for some time and are often classified in regards to chronic depression, distortions in body image, fear of rejection [of the transplant] and grief for the donor. In a review of psychological and psychosocial aspects of solid organ transplant experiences for clinical practice, Rainer, Thompson and Lambros (2010) emphasise Baines and Jindal's recognition of the psychological difficulties of transplant patients and further highlight the deficiencies in managing these psychological problems within clinical practice. They suggest that patients detail personal struggles in clinical practice,



requiring contemplation and reconciliation of their past, present and future life. They further indicate that patients receiving a transplant require a great deal of support following transplantation to reconcile past losses to the chronic illness, to construct a working present and develop new views and future aspirations. Temporal stages have been identified in the organ transplant experience, each with psychological challenges for patients to overcome (Rainer, Thompson and Lambros, 2010); Pre-transplant; Pre-operative/waiting period; Post-transplant.

The Pre-transplant phase includes a formal assessment period, which often marks the beginning of the transplant journey; a long road of deteriorating health and a stage when the illness is seriously evaluated. It can involve a mixture of feelings including distress, ambivalence, hope and anxiety over organ availability vs deteriorating health, death and mortality (Rainer, Thompson and Lambros, 2010). The Pre-operative/waiting period is often seen as the patient's most psychologically stressful time of the transplant experience (Stukas, Dew, Switzer, DiMartini, Lormos and Griffith 1999). Distress is often reported by patients who have uncertain prognosis (Brennan, 2001) and associated with populations waiting for high-risk procedures such as organ-transplant (Kash and Dabney, 2001). Within the Post-transplant period, anxiety and depression are the most noted psychological presentations across all organ transplant disease states (Rainer, Thompson and Lambros, 2010). Other psychological effects post-transplant include limitations in emotional stability, social role functioning and occupational choice. The post-transplant stage is most characterised by major physical and emotional transitions and psychological wellbeing. Dew, Manzetti, Goycoolea, Lee, Zomak, Venzak and Kormos (2002) studied post-transplant psychosocial recovery, aimed at identifying patients at risk for developing diagnosable psychological disorders following transplantation. They found that 22.5% of depressive disorders and 17.7% anxiety disorders were most prevalent between 8-36 months following transplant. Additionally they found that post-traumatic stress disorder (17%) was most evident during the first year following transplant

surgery. Other commonly challenging and psychosocially vulnerable areas raised within transplantation include issues relating to adherence, body image and sexuality, return to work, and support networks and financial strain as reported by Rainer, Thompson and Lambros, 2010.

Data to inform clinical practice in post-transplant psychological care are mostly organ specific (Rainer, Thompson and Lambros, 2010) however still limited within the area of liver transplant to inform clinical intervention. Studies such as Wainwright (1995) have attempted grounded theory analysis of the post-transplant journey exploring the phenomenon of liver transplantation but included only the experiences of participants 12 months post-transplant exploring retrospectively back to the point when patients were called in for transplant. Phenomenological approaches to studying the experience of liver transplant have been carried out from nursing perspectives (Naden and Bjork, 2011; Bjorl and Naden, 2008; Wise, 2002).

## **1.4 Pediatric Liver Transplant**

There is a lot more research in adolescent risk factors, barriers and adjustment than in adult liver transplant. Similar to majority of recent transplant research, studies have predominantly focused on discerning the degree of health related quality of life relative to health controls, with a few studies reporting on health related quality of life compared to functioning prior to transplantation and relative to other chronic illnesses. Fredericks, Zelikovsky, Aujoulat, Hames and Wray (2014) highlight that majority of studies published in Health related quality of life focus on liver transplant experience and to a lesser degree on other solid organ transplants in heart and kidney patients.

Studies on emotional and behavioural functioning for psychological adjustment of pediatric transplant recipients have been mixed, with some studies suggesting adjustment comparable to that of healthy samples and others suggesting impaired functioning with relationships with peers, feeling lonely and socialization skills rated as being more problematic

(Zamberlan, 1992; DeBolt, Stewart, Kennard, Petrik, Andrews, 1995). Fredericks, Zelikovsky, Aujoulat, Hames and Wray (2014) point out some markers for assessing long term pediatric adjustment following liver transplant. These markers include mainly neuropsychological effects, for example cognitive functioning and cognitive ability in childhood as a predictor of educational achievement and regimen adherence and self-management. Non-adherence or poor adherence is noted to be responsible for a quarter of the deaths of the patients with transplants after the initial recovery period (Bunzel and Laederach-Hofmann, 2000). Additional factors and risks associated with poor compliance is often associated with lower socioeconomic groups (Leggett, Orzol, Hulbert-Shearson and Port, 1998); in younger patients (Leggett et al, 1998) and in ethnic minorities (Alexander and Seghal, 1998).

Although we can learn a lot through pediatric samples and there may be some co-occurring issues such as cognitive functioning (not in educational attainment but more in ability to return to work in adulthood) and self-management and adherence; differences are likely to occur in adult patients who have received liver transplants.

## **1.5 Adult liver transplant – review of the literature**

Adult studies of liver transplantation have taken various approaches. Either breaking down the components of liver transplant into their respective phases of pre-transplant, transplant/hospitalisation and post-transplant; or specifically focusing on a core category that has been emphasised within their results. Studies focusing specifically on the recovery period following liver transplantation tend to focus on four aspects: psychiatric; functional aspects (including mobility, endurance, activities of daily living and employment); the psychological impact of unsuccessful transplant; and quality of life (Wainwright, 1995).

Wainwright's (1995) comprehensive review of the literature on recovery following liver transplantation identified earlier studies examining crude outcome criteria such as return to work (Esquivel et al, 1988; Eid et al, 1989; Robinson, Switala, Tarter, Nicholas, 1990). The

studies reported that the majority of surviving patients returned to a more active lifestyle following the operation. Retrospective reports of single (Colonna et al, 1988; Wolcott, Norquist & Busuttill, 1989; Lowe, O'Grady, McEwen & Williams, 1990) and multiple measures of quality of life (Tarter, Erb, Biller, Switala & Van Thiel 1988; Kober, Kuchler, Broelsch, Kremer & Henne-Bruns, 1990; Tarter, Switala, Plail, & Van Thiel, 1991; Bonsel, Essink-Bot, Klompmaker, & Slooff, 1992, Moore, Burrows, Jones, & Hardy, 1992; Moore, Jones, Angus, Hardy, & Burrows 1992; Hicks, Larson, & Ferrans, 1992) similarly showed a dramatic increase in patient quality of life after liver transplant. Following his review of the literature, Wainwright (1995) investigated the process of adjustment that an individual experienced from the point of receiving the liver transplant. Although using grounded theory as his chosen method of analysis and from this, highlighting the transformational experience of liver transplant, Wainwright's study actually takes a more phenomenological approach exploring a patients' experience of receiving a liver transplant. Thus Wainwright struggles to develop a theoretical model at the conclusion of his paper. Instead he discusses the transformational experience that is encountered by liver transplant candidates over time and through this highlights specific areas brought to light in the concept development process. Highlighted themes include the phases of the recovery process e.g. 'Receiving a liver transplant', 'improving in hospital', 'improving at home', 'feeling well again' and 'reciprocating' and within this he highlights common sub-themes such as 'returning to normal', 'needing support', 'being a new person', 'hidden illness' and 'supporting others'.

## **1.6 Liver transplant studies in the nursing literature**

In the handful of other qualitative studies that have been carried out on adult liver transplantation, some have taken the approach of developing specific concepts in more depth. Thomas (1993) took a hermeneutic phenomenological approach to investigating the issue of control for liver transplant recipients. Discussing the dimensions of control within the

transplant experience and how loss of control can impact individual behaviour in patient's efforts to maintain control. Recipients may risk infection and graft failure in an effort to maintain control through manipulating their immunosuppressant regimens or exposing themselves to highly infectious situations. Lumby (1997) further investigated the 'Life/Death' paradox from a critical feminist perspective. Emphasising the balance required by recipients to hold two paradoxical ideas together of maintaining life and optimal wellbeing against the possibility of death taken with the opportunity of transplantation. The study highlighted additional issues of care and caring and also emphasised the role of control as one of the more significant emerging themes from the study. In Nåden & Bjørk, (2012) exploration of the hospital stay following liver transplant, themes tended to reflect the authors and their nursing profession resulting in emerging themes such as 'general contentment with the hospital stay', 'physical discomfort', 'dreams, nightmares and hallucinations', 'Comedowns experienced during rejection of the transplant' and one theme on 'psychological/mental reactions'.

These studies highlight the role the researchers play in the qualitative analysis process and the resulting emerging themes. The above studies emphasise physical and medical areas such as adherence/non-adherence (through maintaining control), side effects (dreams and hallucinations), risk of infection, physical discomfort and life and death. Other relevant but less reported themes mentioned include challenges faced with lack of energy to mobilise and physiotherapy, anxiety and fear of the unknown (Forsberg, A., Bäckman, L., & Möller, 2000) the importance of religious beliefs, psychological support from family, meeting other transplanted patients and pain (Del Barrio, Lacunza, Armendariz, Margall & Asiain, 2004)

Experience of quality of life and psychosocial well-being has a strong subjective component. This qualitative component is lacking from much of the current literature (Engle, 2001). Emphasis has primarily been placed on a transplant recipients' ability to perform everyday tasks and fulfill occupational and social roles and there is a general sense that

transplantation is more concerned with a recipients' functional capabilities and social participation than the subjective experience of individuals. In many ways the liver transplant process of adaptation, quality of life and satisfaction have predominantly been measured by the absence of medical complaints. Previous investigations into liver transplant have been useful in highlighting functional improvement through quantitative studies and barriers and challenges through in depth qualitative interviews with patients who have received a liver transplant. It asks fundamental questions about how patients perceive and experience transplantation from diagnosis to survival and beyond. However, questioning how individuals struggle do not always reflect how patients can be aided in learning to adapt better.

The present study intends to explore how patients who have experienced a liver transplant have adapted throughout the recovery period. The intention is to develop a theoretical model which can potentially inform targeted psychological treatment to encourage and optimise patient recovery following transplantation.

## **CHAPTER 2: A GROUNDED THEORY EXPLORATION OF ADAPTATION FOLLOWING LIVER TRANSPLANT**

### **2.0 METHODOLOGICAL APPROACH**

#### **2.1 Epistemological Perspective**

The specific goal was to examine the process of adaptation to daily living following the experience of receiving a liver transplant. To do this an appropriate research strategy is required. A qualitative approach enables the researcher to enter into the world of the participants, attempting to understand, feel and see the world through another persons' perspective and through doing so, make discoveries that can be further developed into empirical knowledge (Corbin and Strauss, 2008). However, it is also important to explore the different epistemological perspectives which best suit the goals of the research and thus how to approach the data. Exploration of four major points of 'tension' within which the family of qualitative research organises itself ensures the most appropriate form of analysis would be used for the study: a) the role of theory, b) description versus interpretation, d) realism versus relativism, and e) politics (Willig, 2012).

##### **2.1.1 The Role of Theory:**

In this case a primarily inductive process where hypotheses are generated from the data and further tested by investigating new sources of data will be used. Despite the researcher having some previous knowledge, the purpose of the exploration of adaptation is not to look to pre-existing theoretical frameworks because there is a paucity of research and a distinct lack of theory in this area but to encourage emergent theory generated from the data to be tested through further data collection.

Description versus Interpretation: In this study interviews will be used with an intention to analyse participant experiences further to interpret meaning behind their subjective experiences. A mere description from interviews would not enable the depth required to provide a deeper meaning of a participants' account of their experience.

### **2.1.2 Realism versus Relativism:**

Going back to the origins of how this study came about it is clear how important it is that the study help to shed some light on reality and how things are in the world. One of the objectives of the study is to gain some understanding of how patients adapt and recover following liver transplant through the experiences of those who have survived liver transplant. Although there may be some relativist data in reflections of participant experiences that are interpretations and participants trying to make sense of their own and others experiences, essentially the goal is to put these experiences and reflections into the context of the real world.

### **2.1.3 Politics:**

Willig (2012) reasons that qualitative psychology's roots in the critique of positivist psychology. It invests in the idea that qualitative research is there to give those individuals who have previously been excluded from 'traditional' psychological research a 'voice'. Originally this would have included individuals such as women, ethnic minorities, the elderly and others who may be socially excluded. Thus qualitative psychologists have been wary of imposing meaning and pre-conceived theoretical formulations upon individuals' experiences at the risk of 'silencing' participant voices and overlaying our own theories and narratives. In this study the researcher is keen to promote the voice of the patients but is also wary and aware of imposing pre-conceived meaning during the analytical process.

Willig (2008, 2012) suggests that the easiest way for a researcher to access the assumptions they are making of their research, is to ask a series of questions: What kind of



knowledge do I aim to create? What are the assumptions that I make about the (material, social, and psychological) world(s) that I study? How do I conceptualize the role of the researcher in the research process? What is the relationship between myself and the knowledge I aim to generate? For this study, an assumption can be made that there is a hope to create knowledge of the social world and human psychology that can be generated from and used within the real world; that the researcher is likely to play a significant role in the research process through their interpretation of the data generated and the knowledge that the study aims to generate. Therefore this study describes a seeking of realist knowledge which is best suited to a grounded theory methodology.

Grounded theory has provoked a lot of discussion and debate (Corbin & Strauss 2008), questioning which theorists and stance has broadened the methodology in a way that is most faithful to the original intent of producing theory from the data (Boychuk Duchscher and Morgan, 2004; Heath and Cowley, 2004). Disputes have resulted from where various grounded theorists stand between “interpretive” and “positivist” traditions. Thus grounded theory has since diversified since its initial development by Glaser and Straus (1967).

## **2.2 Constructivist and Objectivist Grounded Theory**

Charmaz (2006) juxtapose constructivist and objectivist forms of grounded theory. She describes that “a constructivist approach places priority on the phenomenon of study and sees both data and analysis as created from shared experiences and relationships with participants” (Charmaz, 1990, 1995b, 2000, 2001; Charmaz and Mitchell, 1996). Thus Constructivist grounded theory lies solidly within the interpretive tradition. Charmaz, further explains that Constructivists study how and often also why participants construct meaning and actions in specific situations. Both researchers and research participants are meant to interpret meanings and actions. A constructivist approach not only theorises the interpretative work that research participants do, they also acknowledge the resulting theory

as an interpretation. Researchers using Constructivist grounded theory should take a reflexive stance to the research process considering how their theories evolve. In contrast, an objectivist approach to grounded theory resides in the positivist tradition i.e. “attends to data as real in and of themselves and does not attend to the processes of their production” (Charmaz, 2006). This stance does not factor into account the social context from which the data emerge or the influence of the researcher. An objectivist stance assumes that data represents objective facts about a world that is known, that the data already exists in the world and that the researcher is able to find and discover theory from them. Objectivist grounded theory assumes an external reality which is awaiting discovery and an unbiased researcher who observes and records facts. Careful application of their methods can then produce theoretical understanding.

### **2.3 Grounded theory as an evolving process**

Mills, Bonner and Francis (2006) argue that all variations of grounded theory exist on a methodological spiral and reflect their epistemological underpinnings. The form followed largely depends on the nature of the relationship between the researcher and participant and in the clarification of ‘what can be known’.

Traditional Grounded Theory (Glaser and Strauss, 1967) follows the objectivist approach residing firmly within the positivist tradition. Despite Strauss and Corbin (1994) clearly stating that they do not believe in the existence of a “pre-existing reality” thus rejecting a positivistic position and leaving behind traditional grounded theorists subscription to the ‘discovery of truth emerging from data representative of a ‘real’ reality’ (Glaser, 1978); examination of the literature contains differing opinions about the ontological nature of Strauss and Corbin’s (1994) work (Annells, 1996, 1997; Charmaz, 2000). In discussing the relationship between theory to reality and truth, Strauss and Corbin (1994) state that “theories are embedded ‘in history’ – historical epochs, eras and moments are to be taken into account

in the reaction, judgement, revision and reformulation of theories". This positions them as relativist pragmatists. However, their ongoing work demonstrates a mixture of stances between post-positivism and constructivism. They rely on terms such as recognizing bias and maintaining objectivity when describing the assumed researchers' position regarding the relationship with participants and the data. In the ever evolving methodology of grounded theory Strauss and Corbin (Strauss, 1987; Strauss and Corbin, 1990, 1994, 1998) acknowledge the importance of a multiplicity of perspectives and "truths", thus enabling analysis of data and reconstruction of theory that is richer and more reflective of the context in which participants are situated. Furthermore Strauss and Corbin (1994) emphasise that their grounded theory is interpretative work that must include the perspectives and voice of the people who are studied and therefore participant stories must be related to the world in which participant live.

Following reflection of these epistemological approaches to data, a decision was made to work within Corbin and Strauss's (1994) modified grounded theory approach rather than a classical grounded theory approach or a pure constructionist grounded theory approach. Primarily because unlike Glaser's version of Grounded Theory, Strauss and Corbin do not claim to enter any field completely free from the influence of past experience and knowledge. "Ignorance is not synonymous with producing insider knowledge" (Morse 1994). Furthermore, Grounded Theory's theoretical roots in symbolic interactionism (Blumer, 1969) views it's researchers as social beings whose ideas, experiences and assumptions of the world contribute to understanding social processes (Baker, Wuest & Stern 1992).

From a more practical perspective it is impossible to approach the data with no past experience and knowledge due to how the study topic area was developed (i.e. in conjunction with discussions with the liver transplant coordinators) and due to the researcher being a member of the liver transplant clinical psychology team. For Strauss (1987) both use of the 'self' and literature are seen to be early influences, specific understandings from past

experience and literature may be used to stimulate theoretical sensitivity and generate hypotheses from the data. Thus in line with Mills, Bonner and Francis (2006) suggesting all versions of grounded theory exist on a methodological spiral, Strauss and Corbin’s focus on the provision of tools to use in this process, swings toward some constructivist intent but does not take a full constructivist stance.

There are several key points of difference that have been described above between the traditional grounded theory approach and grounded theory integrating a constructivist approach. Despite these differences there are a number of common characteristics. Corbin and Strauss (2008) present useful methodological approaches and procedures that they have found most useful for analysis of qualitative data. In particular, Corbin and Strauss’s approach to grounded theory is interested in how persons experience events and the meanings that are giving to those experiences. Common characteristics include processes such as theoretical sensitivity, treatment of the literature, coding, diagramming, and identifying the core category. These formal sets of procedures for guiding or gaining credibility for qualitative interpretive inquiry have made grounded theory particularly attractive to researchers from different disciplines, including psychology (2.3.1 Table: Key Grounded Theory Characteristics). Good examples of studies can be found within health psychology (Houston and Venkatesh, 1996; Sque and Payne, 1996) psychotherapy and clinical psychology (Bolger, 1999; Borrill, Iljon-Foreman, 1996).

Characteristics	Details
An iterative process	A process whereby early data collections and analyses inform subsequent sampling and analytical procedures (theoretical sampling) and the analysis always remains open to new emergent possibilities. This process remains open to new

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	emergent possibilities. This process necessitates concurrent involvement in data collection and analysis phases of the research.
Sampling aimed at theory generation	All sampling decisions made are a function of the research question and the ongoing theoretical development. As a result grounded theory research involves both purposive and theoretical sampling.
Creating analytical codes and categories from the data itself	The analytical process through which concepts are identified and their properties and dimensions are discovered in the data. These should be representative of the data itself and cover a wide range of observations.
Advancing theoretical development throughout	A range of techniques can be used to advance theory development during each step of data collection and analysis. The choice of techniques depends on the epistemological and theoretical stance of the researcher
Making systematic comparisons	Making comparisons at every stage of the analysis (e.g. within and between cases or over time) helps to establish analytical distinctions by identifying variations in the patterns to be found in the data.
Theoretical density	It is commonly accepted that there must be evidence of theoretical density or depth to the observations presented, resulting in the presentation of a theory from which hypotheses can be generated. This should also include

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evidence of theoretical saturation (when new data reveals no new theoretical insights)

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**2.3.1 Table: Key Grounded Theory Characteristics** (taken from Hutchison, Johnston & Breckon, 2010)

## **2.4 Grounded Theory through a Psychosocial lens**

The last several years has seen qualitative psychologist engage more with 'interpretation' (Willig, 2012; Willig and Stainton-Rogers, 2008). This was a result of qualitative psychologists' frustration with using research methods that would systematically represent what participants were saying and doing but did not provide insight into participant experiences or why they were having these experiences. Qualitative psychologists had a curiosity to find out more about the social and psychological underpinnings of processes and structures facilitating participant thoughts and actions and therefore turned toward existing psychological and psychoanalytic theories to provide richer interpretations and explanatory models of the data. Frosh and Young (2008) describe psychosocial qualitative psychology as 'binocularity' whereby both a 'ground-up' (focusing on what is there) and a 'top down' (theory-driven) analysis are deployed simultaneously to make sense of the data. Thus a more detailed description of the data is followed by a theoretically informed reading which seeks to explain the occurrence being investigated. The data that is collected for this study will be viewed through a psychological lens, hence readings of interview transcripts collected will be approached by the researcher with curiosity about why participants speak about liver transplant and recovery the way that they do and what motivates them in their actions as unique psychological beings. Psychosocial analysis will be concerned with making links between what the research participants are saying and doing and what their emotional investment are (Willig, 2012)

## **2.5 Using Computer-Assisted Qualitative Data Analysis Software (CAQDAS) to facilitate the grounded theory analysis process**

Advances in computer technology have led to a range of software packages designed to assist qualitative data analysis. However, it has been suggested that CAQDAS can be used to turn qualitative research into automated rigid processes that excludes the role of human interpretation and reflection (Kelle, 1995). Additional concerns raised suggest that CAQDAS promoted the use of complicated analyses without fully understanding the principles of the techniques that are being applied (Johnston, 2006; Weitzman, 2000; Richards, 1998). The debate around use of CAQDAS tends to focus on four main issues: Concerns that the technology can distance researchers from their data; the dominance of code and retrieve methods with the exclusion of other analytic activities; fear that CAQDAS will mechanise the analytical process making it more similar to quantitative 'positivist' approaches; and the misperception that use of CAQDAS will create its own approach to analysis or that it can be only used for Grounded Theory methodology (Bazeley, 2007). These issues will be discussed further below.

### **2.5.1 Closeness and distance:**

Critiques of CAQDAS have suggested that its use can facilitate the loss of closeness to the data via poor screen display, segmentation of text and loss of context, thus risking alienation from the data (Bazeley, 2007; Seidel and Kelle, 1995). Closeness is required for familiarity of the data as well as an appreciation of subtle differences. In contrast the combination of tape recorders and software can create too much closeness to the data, a feeling of being 'bogged down or overwhelmed by the data, and entangling the researcher into a 'coding trap' (Gilbert, 2002; Richards, 1998). Distance is required for abstraction and synthesis. This can prevent the researcher from seeing the 'bigger picture'. More recently created software has been created with closeness and distance in mind and an ability to switch

between the two (Richards, 1998). Closeness is assisted by improving screen display rapid access to data through retrieval of coded text and documents, easy source identification and the ability to retrieve segments of text within the original context. Tools providing distance include modelling features, exploratory and theory testing features and summaries of results, thus taking research beyond basic descriptive analysis to a deeper understanding. Exploiting these characteristics can contribute to a sophisticated qualitative analysis.

### **2.5.2 Code and retrieve methods:**

Early CAQDAS programmes were tools built for storage and retrieval rather than for data analysis as this was what they were best able to do. Computers had the ability to remove the restrictions held by limited paper-based marking and sorting of text and further helped to remove some of the labour of manual coding such as labelling, cutting and filing. Marshall (2002) highlights that “When recoding data involves laborious collation of cut-up slips and creation of new hanging folders, there is little temptation to play with ideas, and much inducement to organise a tight set of codes into which data are shoved without regard to nuance. When an obediently stupid machine cuts and pastes, it is easier to approach data with curiosity – asking ‘what if I cut it this way?’ knowing that changes can be made quickly.”

CAQDAS methods have been blamed for advocating for purely code and retrieve methods to the neglect of extensive memo writing, linking of ideas, viewing texts holistically and visualizing techniques. Accusations have argued that code and retrieve methods stifle creativity and reduce variety as a dominant approach. Despite programmes such as NVivo 10 providing tools and features for memo writing, diary keeping, viewing texts both in abstract and within its holistic context and visual model building; facilities for coding can lead to a tendency to code to the exclusion of other analytic activities (Richards, 2002). When using CAQDAS the researcher must take care to strike a good balance between coding and analyses tools available to them. Used appropriately a combined approach can be taken to coding with reading, reflecting, linking, noting/memoing and doodling/modelling.



### 2.5.3 Mechanisation of analysis:

Fears that computers can take over analytical processes, alienating researchers from the data stem from the association of computers with numeric data processing. Functions within CAQDAS, such as keyword searches within qualitative analysis are almost always secondary to interactive coding of data, if used at all. Similar automated coding processes only have a place in handling routine tasks for example identifying speakers in a focus group or perhaps checking the thoroughness of coding. Automated coding and keyword searches cannot replace meaningful interactive coding.

CAQDAS for all qualitative methodologies: Despite concerns that the use of computers will create its own approach to analysis, the aim of using CAQDAS is that the researcher will integrate their chosen perspective and analytical framework into their choices on what and how to code the data and further, what questions to ask of the data. The software itself is unable to do this. Kelle (1997) argues that the “connection between certain computer-aided strategies and methodological approaches is far more loose than is often assumed. Use of CAQDAS can provide the rigour and transparency akin to the detailed analytical procedures applied in grounded theory hence the regular comparisons to computer software’s appropriate use for specific methodologies such as grounded theory. However the concepts and procedures of grounded theory are clear in providing a variety of useful heuristics, rules of thumb and methodological terminology (as described above) rather than precise methodological rules (Kelle, 1996). Using CAQDAS can be particularly useful and fit well with methods such as Grounded Theory but not to the exclusion of any other qualitative methodology.

Despite these criticisms, if the capacity of computers for recording, sorting, matching and linking can be capitalised on, then the efficiency of the analysis process could be greatly enhanced (Bazeley, 2007). There is general acceptance that if used appropriately CAQDAS can

enhance data analysis (Bringer et al, 2004; Bringer, Johnston and Brackenridge, 2006a, 2006b; Johnston, 2006).

Bringer, Johnston & Brackenridge (2006a) have specifically demonstrated how CAQDAS using QSR-NVivo (version 1) has been used to successfully facilitate the use of a grounded theory analysis. NVivo enabled the investigation to move from thick description to an explanatory model grounded in the data, further providing a transparent account which ultimately enhances study validity (Bringer et al, 2004). Hutchinson, Johnston and Breckon (2010), with NVivo (versions 7 and 8) used grounded theory analysis to investigate how people successfully changed their physical activity habits in order to improve their own personal health and/or wellbeing. They found that NVivo was able to facilitate many of the key characteristics of a grounded theory approach. They demonstrated methods that can be used to enhance grounded theory analysis using Nvivo. Based on NVivo's ability to aid movement between closeness and distance from the data, through the preciseness of coding, memoing and visualising potential theoretical avenues through models; a decision was made to use NVivo (version 10) to facilitate the grounded theory analysis for this study. The researcher was also particularly attracted to the complete transparency in the analytical process through using NVivo, which would enable her learning in both grounded theory and use of CAQDAS. In a paper discussing the assessment of quality in qualitative research, Mays and Pope (2000) discuss two views of how qualitative research can be assessed according to two broad criteria: validity and relevance. In assessing validity, "a clear exposition of methods of data collection and analysis" is essential, as the methods used in research unavoidably influences the phenomenon under investigation. CAQDAS systems such as NVivo emphasise transparency to assist the researcher to reflect upon the questions and decisions made throughout the analysis process.

## **2.6 Sample, Eligibility and Recruitment**

### **2.6.1 Sample:**

Patients were selected in collaboration with the Liver Transplant Co-ordinators. Eleven participants were recruited altogether for interviewing. After discussions with the Liver Transplant Coordinator team lead, a decision was made to select patients after they had been discharged from their initial hospital admission following transplantation. This decision was made out of respect for the patients recovery and also because it may be difficult to approach patients for participation whilst they are still heavily under the influence of pain medication on the ward. Following a patients discharge, patients will be regularly attending weekly follow up appointments with the Liver transplant team, this will provide a more practical time to approach patients following transplantation for participation. Selecting patients for participation following discharge will enable the majority of patients to have dealt with the immediate physical complications post-transplant, to have had time to reflect upon their life since transplantation and provide a retrospective perspective of how they have coped and adapted.

The liver service in the Royal Free Hospital caters for adults from the age of 18. In this study a representative sample of the population presenting for transplant (within the age range of approximately 40-60) will be captured for interview.

### **2.6.2 Eligibility:**

As liver transplant patients receive some psychological screening from clinic staff during their 'work-up' process, those with more extensive psychological difficulties were likely to be suspended from transplantation until their problems have been resolved. Patients were excluded if their transplant has been found to be chronically failing within the first 6 months post-transplantation. Patients identified with having severe psychiatric problems post-

transplant, unrelated to the transplantation would require more specialised psychiatric treatment and would therefore not be suitable for the study. However this did not exclude patients who were experiencing some psychological problems which had arisen from the transplant process, from participating in the study. In considering substance misuse and co-morbidities such as alcoholism, a pre-requisite to transplantation in the Royal Free Hospital, required that the patient be abstinent for a period of time (often this would be a period of approximately 6 months) until such time that the liver transplant team agreed to proceed with the transplant process. Other co-morbidities which may have contributed to the liver disease/damage (e.g. Hepatitis C, Cancer) were not excluded from the study.

### **2.6.3 Recruitment:**

Initial recruitment of patients required that they be approached when they were attending their routine post-transplant follow up appointments, by either the Liver coordinators or by a member of the Clinical Health Psychology team. Patients could also be identified by the Liver Transplant Coordinators and then contacted via a letter posted to their home address from the Clinical Health Psychology Service. Once approached or contacted via letter, patients were provided information leaflets about the study and asked if they would like to participate. If so, consent for participation was requested within 14 days. Patients could decide to withdraw prior to interview, and once interview data has been collected participants had a two week period in which they could contact the researcher to have their data withdrawn from the study.

Recruitment in the first 6 months was very slow with only one participant consenting to be interviewed. This prompted for amendments to be made to NHS ethics and ethical approval from the university to be sought for online recruitment.

#### **2.6.4 NHS recruitment:**

After NHS ethical approval was confirmed, several methods of referral and for participants to contact the researcher were made available (See Appendix 1: Recruitment Documentation):-

1. Participants could consent to take part by directly contact the researcher by phone.
2. Participants could consent to take part by letting one of the liver transplant team know.
3. Participants could consent to take part by directly contacting the researcher by email.
4. Participants could consent to take part by contacting the researcher by post.
5. If the researcher has not heard from potential participants within 14 days, the researcher is able to directly call the participant if necessary.

#### **2.6.5 Online recruitment:**

Internet recruitment will be carried out through a step by step process:-

1. Contact support groups, charities and organisations working with people who have received a liver transplant
2. Advertise through their websites and email lists or postal lists.
3. Website organisers may also suggest individuals who they work with who might be interested in taking part.

All potential participants would then be sent by email or post an information leaflet explaining the study and a reply form with Freepost return envelope (See Appendix 1: Recruitment Documentation).

Twenty eight participants consented to be contacted for interview via the freepost envelopes. However, only a further ten participants were contactable and consented to interview through NHS recruitment, meeting the minimum target of eight participants. At this

point a decision was made that enough data had been gathered to be able to explore the process of adaptation following a liver transplant (see *Saturation*).

### **2.6.6 Theoretical Sampling:**

Due to the practicalities of carrying out a grounded theory study within the NHS, theoretical sampling was a challenge. NHS ethics is a required and a necessary step all research must adhere to when carrying out a project within the NHS. However, its necessity often causes restrictions which make more flexible qualitative approaches difficult to carry out. In the case of the grounded theory approach this study intended to use, it caused restrictions on the use of methodological approaches such as theoretical sampling and saturation. For NHS ethics, a minimum sample of 8 participants was set for the study however it was difficult to specify the number of participants required for adequate data and data saturation. Theoretical sampling is based on concepts and themes that are derived from the data with an aim to collect data from individuals that will maximise opportunities to develop concepts. This enables the researcher to select participants to further inform an understanding of a specific area of interest based on the emerging theoretical constructs from the data gathered and a process of constant comparison and analysis. Online recruitment could be a particularly useful source for sampling around a particular phenomenon such as Liver transplant. This is critical for the development of a substantive theory (Strauss and Corbin, 1998). This study was unfortunately not able to carry out theoretical sampling in the standard way Strauss and Corbin suggests it most useful, however, the researcher took care to listen back to all interview data prior to interviewing the next participant to ensure any new or emerging avenues, through this brief method, could be identified and further investigated in the next interview.

### 2.6.7 Saturation:

Saturation is a topic with diverse opinions. With any qualitative research samples must be large enough to assure that most or all of the important topic areas are uncovered. However if the sample is too large data can become repetitive and made redundant. Ideally qualitative researchers should remain faithful to the principles of qualitative research i.e. sample size should follow the general concept of saturation, when the collection of new data does not produce any further information on the issue under investigation (Glaser and Strauss, 1967).

Charmaz (2006) reports that the study aims should ultimately be the driver of the project design and therefore the sample size. Thus a study with smaller 'claims' is likely to achieve saturation quicker. Other arguments suggest that the concept of saturation is inappropriate (Dey, 1999), as researchers can close categories early even if data is only partially coded. Dey, cites Strauss and Corbin (1998) to support his argument, who suggest that saturation is a "matter of degree". They report that the longer a researcher examines, familiarises and analyses the data there will always be the potential for new data to emerge. They conclude that saturation should be concerned with recognising a point where examination of the data becomes "counter-productive" and that anything "new" discovered would not necessarily add to the overall theoretical framework or model. Additionally they admit that sometimes developing a conclusion to their work is not necessarily a lack of data but an excess of it. A further issue is the ability to apply the concept of saturation within a time and resource limited doctorate research study. On a practical level, NHS ethics also required a thorough proposal, including a detailed description of who, where and how many people would be interviewed prior to starting the research. Considering the restraints within which the researcher was required to work as part of a doctoral study and within the constraints of recruitment within the NHS, in this study the research sought to work within a more practical framework.

Riley (1996) states that majority of studies achieve saturation within 8 to 24 interviews. Guest, Bunce, Johnson (2008) support this by suggesting that saturation, for the purpose of

data presentation and discussion, is most likely to occur earlier in the analysis process. In their paper analysing qualitative methodology processes they suggested that enough data existed after 6 interviews to support their 4 themes. The 'magic number' of 6 interviews was also consistent with Morse's (1994) recommendation for phenomenological studies and Nielsen and Landauer (1993); who proposes that 6 participants can uncover 80% of problems within a system.

Based on this information, this study aimed to interview between 8 to 15 at the outset. After recruiting 11 consenting participants through the NHS recruitment system set up, no further participants contacted the researcher and a decision was made to end recruitment. However the researcher was open to receiving and investigating other sources of data which enabled further development of the constructs arising through the interview data. For example one participant returned to the researcher to provide digital diaries that were made throughout his personal experience of having a liver transplant. This included drawings and pieces of art and poetry.

#### **2.6.8 Interview Procedure:**

One to one interviews were carried out with consenting participants who had received a liver transplant. More unstructured methods were used during initial interviews to allow respondents to use their own way of defining their world. A very brief interview schedule helped the researcher to keep the research aims in mind to ensure the interview continued to provide relevant information (Appendix 2: Initial interview schedule).

Following the first interview there was a gap in recruitment due to lack of participants and time required for amendments to be made for ethics, to try to increase potential consenting participants, as mentioned previously. However this gap in recruitment provided time for the first interview to be transcribed and initial analyses to be made. This enabled some use of theoretical sampling to provoke thought in how and what data was collected based on concepts arising from the first interview. The interview schedule was then adapted to include



further questions to be asked within interview with subsequent interviews becoming more semi-structured and focused in methodology. Interviews carried out were a maximum of 90 minutes in length (including any breaks required by request of the participant).

### **2.6.9 Data analysis:**

Corbin and Strauss's (2008) book on qualitative research guided the process of analysing the data. Analysis began with the process of 'open coding', described by Corbin and Strauss (2008) as a 'brainstorming approach to analysis to 'open up the data to all potentials and possibilities contained within them'. At this point the researcher used NVivo to scrutinise the transcripts to an in depth level in an attempt to draw out the essence of what the participant is attempting to express. Here the analytic focus was mainly to construct concepts from the data. All emerging concepts were relevant at this point enabling the data to provide what was most important to the participant and so that analysis was minimally influenced by 'research expectations'. As mentioned previously, thought of analysis began following the first interview. The gap in recruitment enabled the recording to be listened to and thoughts about the first interview emerged during transcription. Subsequent interviews built on thoughts that were recorded via memo notes as concepts were identified and labelled. Corbin and Strauss (2008) note that computers can be used for the coding (as was the case in this study), however the analyst must take care not to fall into the trap of 'labelling' without being reflective about what the data is indicating. Thus care was taken to ensure that 'thinking' was at the heart of the process and thoughts and memos recorded. Although not all concepts from memo notes developed further into themes/categories, the process of recording memos from the point of interview through to analyses supported the researchers' analytical thinking over time.

In a second stage of analysis, the researcher focused more on the question directing data collection. Thus the underlying process became the focus within the data and how participants experienced their adaptation post-transplant. Corbin and Strauss (2008) name this stage of coding 'Axial coding', defining it as 'the act of relating concepts/categories to each

other'. During this stage memo notes were also used for reflecting back on potential questions and hypotheses initially drawn from the data for further development into categories. Further analysis of the patterns and interactions flowing throughout the data enabled the final stage of integration; where categories link around a core category. Through this process the research analyser was able to develop a hypothesis of a theoretical concept of the process of adaptation post-liver transplant.

## **CHAPTER 3: DEVELOPING AN EXPLANATORY THEORY FOR THE ADAPTATION PROCESS**

### **3.0 INTRODUCTION TO FINDINGS**

One of the unique outcomes and goals of Grounded Theory is to develop an explanatory theory of basic social processes (Glaser and Strauss, 1967). Glaser (2002) explored the use of grounded theory to 'generate conceptualisations of emergent social patterns in the research data'. Through abstraction of time, place and people, and the constant comparative method, patterns can be named and enhance conceptualisation to form emergent theories. Glaser highlights that the most important property of conceptualisation for Grounded theory is that 'it is abstract of time, place and people'.

In 1995 Wainwright published a grounded theory study exploring 'The Transformational experience of liver transplantation', unable to remove conceptualisation from 'time, place and the people'; Wainwright orientated his transformational experience through a 'five-stage trajectory of receiving the transplant, improving in hospital, improving at home, feeling well again, and reciprocating. He attempted a grounded theory analysis of the post-transplant journey exploring the phenomenon of liver transplantation but included only the experiences of participants 12 months post-transplant exploring retrospectively back to the point when patients were called in for transplant. The temptation is indeed to follow a similar pattern of orientation in this study, as the stages of transplant and recovery appear quite explicit in the data. However, through structuring the concepts around descriptive elements of time and place, the researcher is unable to fully and abstractly develop concepts. As this study's findings are explored further, you will be taken through a journey through the researchers thinking and of the development of the concepts towards a core concept and

eventually a discussion of potential theory that relates to the process of adaptation in patients with a liver transplant.

Findings will be explored in two stages, firstly acknowledging the 'phenomenon of having a liver transplant' (Chapter 4). Secondly, (through the abstraction of time, place and people) concepts are developed into the form of 'protective factors' (Chapter 5). A final and third section will bring the previous two sections together to develop a core concept of 'Resilience' and propose a theoretical understanding of the process of adaptation. A cross over of conceptual ideas may be indicated across the sections, and further depth and exploration of theory will be highlighted as the sections progress.

## **CHAPTER 4: EXPLORING THE PHENOMENON OF HAVING A LIVER**

### **TRANSPLANT: THE TRANSPLANT JOURNEY**

#### **4.0 THE TRANSPLANT JOURNEY**

Exploration of the phenomenon of having a liver transplant by detailing the steps from diagnosis through to post-transplant recovery became an important process in itself for participants contributing to this study. It is also recognised that the researcher asks participants to begin to orientate themselves and the interviewer by starting where they felt their journey first began. For all participants they began by discussing either the cause of their illness or the symptoms leading to diagnosis itself. Not only is it important to consider the pre-transplant experiences because participants discussed this with equal importance but also because pre-transplant experiences can also point toward individual differences and past behaviour impacting the process of recovery. For participants, storytelling was a way of making meaning of their experiences. Several previous studies have taken a hermeneutic phenomenological approach to studying the phenomenon of liver transplant (Nåden & Bjørk, 2012; Bjørk, & Nåden, 2008; Wise, 2002; Thomas, 1993;). These studies were approached from a nursing perspective. However, none have approached the complex experience through a psychological perspective within the larger context of a grounded theory study.

#### **4.1 Diagnosis**

Experiences of identifying a need for a liver transplant were varied. Diagnosis would often take a period of months of investigation in which participants were continuing to suffer from a number of symptoms whose causes were in some cases unidentifiable. In some cases (participants 20 and 25) probable causes were identified but no definite underlying cause. However through the delay in timely referral to specialist liver services and identification of the problem, symptoms worsened increasing the risk of hospital stays. This was not a

reflection of any one particular hospital but highlighted the speciality of knowledge in hepatology services in the UK and its limited availability in only certain hospital locations.

They didn't test liver function. Um, then when he couldn't work out what it was, because by this time my abdomen was starting to swell as well, er, he referred me to, um, a gastroenterology consultant at HW Hospital, um, who thought it was probably irritable bowel syndrome. Um, and by this... oh, you can imagine, a month, six weeks or so have gone by, by now, um, and I was still no further forward and then I got to a point where I was having real difficulty breathing. Um, so I 'phoned the GP for an emergency appointment and he said, you need to go into hospital now, um, and do something, so, um, I went into A&E and it turned out that there was so much fluid, um, that it had pushed its way up into one of my lungs, and the lung collapsed ..... So that's what was causing all the breathing problems. Um, so I ended up in HW hospital for a month, er, while they drained it off, did various tests.

Participant 20

For these two individuals (participants 20 and 25) it was important to explain that the cause of their end stage liver disease had not been caused by some of the more commonly known routes e.g. alcohol or substance misuse.

Nothing was conclusive, um, I... of, of the known liver related things, like hepatitis, alcohol, um, those sort of things, I hadn't had any of that. Um, the only instance where I'd previously had liver tests was in 1994 when I'd had cancer and the treatment... they kept an eye on my liver because they were concerned it was going to damage my liver. Um, and the conclusion that Dr DP came to in the end was that that must be what's caused it...

Participant 20

I believe that the problem was initially caused by, er, some prescription drugs that I was on for a very long time, er, many years ago, er, and my liver was somewhat

damaged. Er, I never, er, drank a great deal in terms of alcohol, I was not a great drinker.

Participant 25

Participant	Gender	Year born	Original Cause	Secondary diagnosis	Tertiary diagnosis
1	F	1953	Breast cancer		
13	M	1960	Hepatitis C	Cancer	
14	M	1967	Alcoholism		
16	M	1961	Intravenous Misuse	substance Hepatitis C	Cancer
19	M	1958	Hepatitis C	Cancer	
20	M	1959	Unknown/possibly diagnosis of cancer	past	
22	F	1969	Primary Sclerosing Cholangitis (PSC)		
23	M	1957	Alcoholism		



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<b>24</b>	F	1972	Cancer
<b>25</b>	M	1946	Unknown/possible prescription drugs
<b>28</b>	F	1988	Glycogen Storage Disease

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*4.1.1 Table: Known causes of End Stage Liver Disease requiring Liver Transplantation as treatment*

Cancer or cancer caused by damage from Hepatitis C virus (HCV) was also commonly reported when talking about diagnoses. End-stage liver disease secondary to HCV is the leading indication for liver transplantation in the United States and recurrence of the infection is universal (Chalton et al 1998) so it did not seem unusual to have several participants discuss this origin of cause. Three participants identified the origins of their illness to be caused by alcohol or substance dependence. Local alcohol profiles for England (Jones, Bellis, Dedman, Sumnal & Tocque, 2008) indicate that hospital admissions for alcohol related disease including alcohol related liver disease has seen a 71% increase between 2002/3 and 2006/7, indicating that it would not be unusual for a number of participants to report alcohol/substance as a primary cause for illness.

There was minimal discussion about how diagnosis impacted participants emotionally, the focus was more on prognosis and the required next steps for treatment. Participants 13, 16 and 23 reflected a level of acceptance and almost detachment from the news that had been received, with reactions such as:

Oh, okay then, what do we do, kind of thing, about it? No panic or excitement, kind of thing. It was just, okay then, that's... well, we do what we've got to do.

Participant 13

No, no, no, I didn't feel different at all. I just asked... I just wanted to know, you know, what one's life expectancy was and how, you know, if it was treatable and so on and so forth. And, er, you know, that's what I got, so.

Participant 16

So now I've got to deal with what I've got, ah, and that's what I was trying to do

Participant 23

Usually treatment plans were made quite rapidly after identification of the cause and diagnosis due to the seriousness of the condition. Realising that transplantation was the next step was often the more shocking news than the diagnosis itself.

The cancer was diagnosed in the liver in May last year, May the 25th I think and they said a good first step would be to look at transplantation and I went 'wow! That sounds like some first step!' and they said, 'Well, it will kill you in 2 years, erm, so we ought to look at putting you on the waiting list'. I did that week in June

Participant 19

## 4.2 Pre-Transplant

A few core issues were discussed within the pre-transplant phase including information, preparation and thoughts around death and dying. For some the pre-transplant process, tests and information felt overwhelming to the lay person.

It's so much information. It's very difficult for lay people, and I know they simplify it as much as they can for the patients but, er, nonetheless it's, er, it's complex.

Participant 16

Um, I was quite staggered by all the different processes and all the different tests, even though it's explained to you, and you have a booklet of what's going to go on, um, and they tell you what the tests are for, that... what they're looking for. I think the funniest one was, you have these things stuck on your head to look at brain activity

Participant 22

For many participants, preparation was key and highlighted to the individuals the fragility of life and a reflection of their mortality. A few of the participants' acts of preparation carried out prior to transplantation reflected their thoughts about the real possibility of dying and in particular, their concern for loved ones should anything happen during the operation.

The paradox between a solution for life (transplantation) and the possibility of death has been highlighted in other phenomenological studies as a core feature of the pre-transplant experience (Lumby, 1997; Forsberg, Bäckman, & Möller, 2000; Brown, Sorrell, McClaren, & Creswell, 2006)

Then I told everybody exactly what to do with my horses, what would happen to them, um...that was a big worry of mine. Who would look after them if I was in hospital, let alone if I died coz I had 12 horses and that's a big responsibility.

Participant 1

P: I said, 'no M, we need to talk, and I need quiet now before my operation' and I made a list of how to do the electricity key, my bank details. I made a will some years ago, told her where that was, um gas, um, standing orders etc ....

I: Why did you feel you had to do that?

P: Just in case I died

Participant 19

...but one thing I, kind of, did was really odd, just literally about two weeks before the transplant, I just, I put a lot of things in order. Like, so, I arranged for... it sounds really... this how control freakish I am; I did, like, a... I remember going on Sainsbury's online and doing a shop and keeping it, you know, like, as a favourite list, like I did a basics list and a favourites list, kind of, two different shopping lists, called them whatever, saved them, and told my daughter, I said, look, you know, so that you can shop for J when he comes, just push, you know, send and, and here are... and do this, and here's my bank details, you know.

Participant 22

That... I couldn't do anything about it and the only thing I could do about it was to make sure that I lived as well as I possibly could. Um, so obviously low salt, putting as... the least amount of stress on what was left of my liver, um, and then I'd try to get myself as fit as I could..... the consultants have said to me, look, you must do this because if your body is in a reasonable state of fitness your recovery is going to be so much better...Well, I, I know that the... on, on average, I think it... I think the numbers are correct; that there's 650 people a year on the transplant list and of those 650 generally about 150 don't make it to the transplant stage. So, yes, that's always a... you know, sitting at the back of your mind. But again, it's something you can't control, and so the only way you have around it, or I have around it, is by making sure that I stick to whatever I can to make it as better... as good as possible.

Participant 23

### 4.3 Transplant

The actual transplant highlights a point in the process when the situation actually becomes reality. For three participants the first call for transplantation was not suitable and it was only after the second transplant that there is a suitable match. This brought a mixture of feelings and thoughts of "what if?" but also relief that the operation did not go ahead.

...and was thinking, oh, grief, you know, could have had it done, that would have been great, but in a way I was relieved because it hadn't been done.

Participant 23

This 'practice run' provided some participants the opportunity to adjust to the reality of the situation and prepare more thoroughly for the operation.

I'd already had, I had one fall through, which they came in and they prepared me....

So it brought everything to light. Everybody... it was just talk before that, yeah? And all of a sudden, when this call, that was... well the, the call, the... the second call, I mean, that was totally different.

Participant 13

At the point of going into surgery 'reality hits home' and each participant discussed their experience with varying states of mind. Several participants talked about feeling quite calm whereas some described even being excited for the possibility of a 'new start' (participant 16). Participant 1 described the mixture of calmness on the surface within the race to have everything ready for the operation, yet anxiety and excitement underneath.

No, I was very calm, inside I was turmoil I'm sure. I think you get to a point, you cannot be anymore frightened. It's almost like...I am so sick of feeling this fear...I can't feel it anymore. And it goes, it really does. I don't know why or how, but that's gone.

Participant 1

*As an Inpatient:* The post operation process involved many challenges both mental and physical for recovery. Initial thoughts for patients post-surgery were their memory or loss of memory when waking up in intensive care. For some participants the post-surgical side effects of the anaesthesia and morphine caused an enormous amount of distress and were particularly frightening. For others, intensive care was vague and distant in their memory.

It was as though I was living in three worlds at the same time, it's the most [pause] disconcerting thing, because you didn't know who was real. There were, [pause] there were people that, er, you know, I, they must have been inventions of mine but they were so correct in every detail, you know, they'd [unclear] JW who, er, was in my ward, said, you know, J, you were rambling, talking, talking to people that weren't there and all this sort of thing, but to me they, those people were absolutely real. As real as you are, and in every detail, you know, real...

But that, to me, was a great relief. Suddenly I could say, ah, it's the drugs, it's the drugs! That's what's happening. And that was the moment that I started to work out what was real and what wasn't real...

Oh, well, you don't relate it to things. It, it, it's all so, you're in such a, er, tumultuous mental state that the operation becomes a complete side issue, you know. You, you imagine that everyone's trying to kill you, and in those circumstances you, you know, it's, it's [pause] they're very dangerous circumstances because, yeah, I, I'm just most grateful that I didn't actually hurt anyone. I think I was in quite... I was quite capable of doing so. I'm afraid to say. I'm just very grateful that I didn't.

Participant 16

Um, yes. I, I, I remember being in ITU but not very much, and I had no idea as to how long I'd been there; none at all. And I was quite surprised. My wife told me I'd been in there for nearly a week, and I hadn't really come round for several days and when I came round she said that I had been, something like, inappropriate or something, things going all over the place and so on. And then they put me under again and, um, er, all of this is, is not from me, this is from what I've heard from others.

Participant 20

Majority of participants' main goal was to be discharged from hospital and begin recovery at home. Various messages were put across from health care practitioners to encourage health behaviours that would optimise recovery, health and hasten discharge. For majority of participants in the study this would often incentivise and motivate them to increase positive health behaviours for recovery. Often they would demonstrate a self-determination and drive, fuelled by a need to get better. Once they realised what they had to do, determination helped them set their minds on the objectives for recovery. Finding their motivation to start mobilising was highlighted as an important part of the recovery process.

The thing they said, the more you move, the quicker you can go home.

Participant 1

I found the motivation was, I need to drink, but the horror I'm seeing when I seen my legs was, no, you can't drink, your skin's going to burst open, yeah? But, if you start moving, which I was told to do, so that's all I would do, and your little hospital paper cups, yeah? So I thought, walk down to the water, didn't care there wasn't a lock on the door, I didn't care, right?

Participant 13

Physiotherapist said 'right, we want you up!' and I went 'what now?!' coz I was feeling very delicate and he said 'yeah, you'll feel better.' and I found that to be enormously helpful because within 2 days I was wandering up and down, and right the way down to there [indicates] and he said 'try and get up and walk, 2 or 3 times a day if you can' and so that was another sort of thing to do really, the problem with phlegm on the chest is appalling, coz you can't cough [makes choking sounds] and I remember feeling shit, and it seemed to really help that. The phlegm went quite quickly from walking around, whereas the people who didn't, because you do have to force yourself, they didn't recover in anything like the same way, you know they'd still be lying in bed really.

Participant 19

So I was then determined, um, to just get well as quickly as possible, and I was, I was out of bed as soon as I can. Um, you know, it was the little things, little things I was determined to do, like I never wanted to wee into a bottle while sitting in bed. I was determined I would make it to the toilet, how, however hard that...

Participant 20



They said, you know, when you first stand up, you know, it's quite a big thing, because you, sort of, lose your legs, really. Um, but it wasn't as bad as I'd, sort of, anticipated

Participant 24

I was determined to get up. I was determined to get up and about as soon as I possibly could, but I remember on the, er, one of the early occasions, um, I tried to get out of bed; my son was there and my wife and, er, my son's wife were there, and I tried to go out into the corridor and my legs wouldn't hold up... hold me up, and I was staggering and he was hanging on to me so I didn't fall over and so on, and it was, er, it was pretty poor. And then the physios came along the next, I think it's the next day, and they tried as well, er, but I needed the support of the, the stuff. But it wasn't very long; I, I was, I kept on at it and was up, 'cause I didn't want to stay in bed, I wanted to get up and sit up in the chair and get out, um, 'cause I, I was aware that the sooner I could get myself mobile the better.

Participant 25

On the other hand, some participants were more reluctant to mobilise for fear that they would cause more harm than improvement or as participant 28 explained that she did just enough to reach the goal of discharge. Participant 14 would rely more heavily on support from health care professionals, particularly physiotherapists and was less likely to initiate mobilisation without the support of a trained professional.

And it took time, 'cause every time we said, oh, you know, okay, with the physio, all right, we'll go and try a set of stairs, something else would crop up and the physio would be busy and wouldn't be able to spare the time, 'cause some sort of, you know, something more urgent, someone in more difficulty had come up and said, okay, all right, I'm, I'm getting round, you know, with, with the zimmer frame or with the stick, well, okay, no, we'll, we'll do it tomorrow, sort of thing.

Participant 14

I had no confidence in moving around...

Participant 23

And, um, there they would really encourage me to get up and move and, um, I just remember thinking, it's so much more comfortable in bed. Um, but that was just the laziness kicking in, not, not just because I didn't want to do it but I was just getting lazy, not because I couldn't do it....

Um, and I remember, um, somebody said to me, look, if you want to leave early then Dr P has to see you walking around. So I'd make sure that, um, you know, I'd keep walking round and round and round until Dr P had seen me...

Participant 28

Other steps to discharge were related to the essential transplant medications post-transplant patients are required to take, including immunosuppressant's and steroids. Health care professionals would try to prepare patients in managing their post-transplant medication prior to discharge due to how vital medication is to minimise post-transplant rejection.

And they keep telling me I've got a little exam to do before I'm allowed out, which is, is basically, er, you've got to learn all your tablets, all your different colours, and things like this. And [unclear] when you're... when I was under the influence it was actually quite stressful, thinking, I'm not going to get out of here, because I hadn't got a clue what any of these tablets are. [Pause] I'm only taking them because I'm told to take them, and if I don't take them I'm going to die, so... but why should I have to know what they are? But I couldn't study anyway, I couldn't, I couldn't concentrate for more than two seconds.

Participant 13

They were always explaining the tablets to you, um, there's just lots of explaining, explaining all the way through and...

Yeah, no, no, very helpful, yeah, because you, I mean, you know, 'cause you don't see the tablets prior to that, you know, you have this concoction of stuff and, um, of tablets and the rest

Participant 22

A vital component for recovery throughout the transplantation process was the social support from family, close friends and the health care professionals. However, the networks and friendships that were built on the ward were a key aspect of the experience. Participants found strength in sharing similar experiences with peers, development of camaraderie in some cases, competition with peers often helped to motivate, learning from others and even a sense of duty to encourage others improvement and healthy behaviours.

I found the sense of spirit and team, the whole community of the transplant ward is really brilliant and when you meet someone afterwards a couple of times have been distressing because they'd deteriorated badly in one case, the cancer had come back. You know you talk to them and go "how are you doing".. "oh, I got an infection and had to come back" "oh really?" and you're all trading stories and again you sort of talk about your experience on the ward

Participant 19

sometimes when I come to clinic I go up to the ward as well, just because I know there's still some people in there that, um, have been in there, and the nurses...it's all big hugs and kisses, and it's like coming back into a family unit, so there's a lovely... between the ex-patients there's a lovely camaraderie,

Participant 20

During the process also I met two other women on the ward who'd had transplants; one who's been, had, who I've made friends with and she's had a living donor

transplant so it was quite interesting seeing someone who was post-transplant, what they looked like, kind of, how it had affected them.

Participant 22

And then I was moved into another room, um, and I got really friendly with the women in there, um, and so we were... actually there was, there was three of us, 'cause there's four beds in a, a ward, um, and, and one bed, you know, we had a turnover of patient but at one point we got really quite, um, sort of, er, territorial, we were terrible! 'Cause we were together, sort of, three or four weeks and that's an awful long time so, um, it was, you know, they wanted to move one of us at one point; it was, like, no, we're all staying together, because we just used to sit and chat, and, you know, you, you do... it's, it's odd when you're in hospital, you do talk to people, um, and they know all sorts... you tell them about all sorts of things that you would never tell anybody else that you meet, sort of, anywhere else after, you know, sort of, straight off... um, so, yeah, we did have some giggles as well.

Participant 24

...when he'd been brought down, he was flat refusing to take any tablets whatsoever, right? And I remember that very clear, thinking, why is he not taking his tablets? If he doesn't take the tablets he'll die. And I remember the nurse would tell him, your wife just left, but we will call her if you refuse to take these tablets. "I ain't taking them, I ain't taking them". And I remember saying, when, once I kind of spoke to him, he'd mentioned about me talked rubbish, and I mentioned the fact that he was talking rubbish with tablets, and we both realised we were both talking rubbish, yeah?

Participant 19

Discharge itself was viewed as an achievement. All participants, with the exception of participant 24, (who due to a more unusual diagnosis and several post-transplant complications stayed in hospital for a much longer period) believed that they had improved

quickly and discharged earlier than they had expected. Some were very eager to be discharged sooner, whether they were medically ready to leave or not, and others were more wary about leaving the safety of the hospital. Table 2 indicates the time frame in which participants were discharged and thoughts and feelings regarding discharge at the time.

Participant No	Discharge Day	Notes
1	10	"No, no. I was out of hospital within 10 days."
13	16-17	<p>"I left here in day 16, it was day 16 or day 17, after the transplant, which is a great, kind of, time period, yeah?</p> <p>But I was wanting out, I was wanting out by day 10, but I thought it was... I... remember, I thought I was in for... I thought I'd been in for four weeks"</p>
14	24-25	<p>"That was about three and a half weeks, I mean, even then it was quicker than expected, and I was expecting...</p> <p>obviously I was looking forward to getting home and, and no, well, you know, I was still wary about, well, is it too early? Am I, am I... how am I going to cope?"</p>
16	42	<p>"Well, I was very relieved to be out of hospital, needless to say. And, um, you know, to be in familiar surroundings calmed me a lot, and, you know, I could sleep a bit better and, you know, so things... a sense of normality really came back to me. It was just wishing to escape from the hospital and having done that, yeah, really helped me. So I... when the doctor said I could go home I, I nearly jumped out the bed and kissed him, you know, I... it... you know, it's great news, so."</p>

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<b>19</b>	11	“Dr O, said you're looking too well to be here, you know, we've got to get you out, that was all only after 7 or 8 days, my best friend Jodie who had come up from Brighton, her first comment was, 2 days after the operation, was, 'you bastard! you bastard! what you put us through! you've done it again! look how well you're looking! how many times have you...!' you know she was just giving me hell because I was looking very well after just 3 days. Erm, so I was released after 11 days”
<b>20</b>	18	“So I went home on day 18 after the transplant [pause] um, which was fantastic. I mean, once I got home I was... it... [pause] they give you a lot of information, but it doesn't prepare you for what it's actually going to be like.”
<b>22</b>	13	“They were really pleased 'cause, I mean, I, I got out of here in 13 days so it was quick, you know.”
<b>23</b>	14	“Now. But as I say the first... because I recovered so well from the operation, um, they wanted to send me home after two weeks. And then... and I... but I didn't feel comfortable with that at all.”

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<b>24</b>	About 10 weeks (70 days)	<p>“...I ended up being in for ten weeks due to lots of other complications.</p> <p>Um, I had rejection, I think, the second week, um, and I think at the time I didn’t realise it was, sort of, as a big a deal as it was, but that it, you know, clearly was. Um, and then, I can’t remember how many weeks in it was, I think was on the fourth week, um, I started getting fluid on my lung...”</p>
<b>25</b>	14-20	<p>“Oh, about, er, two weeks after that, maybe.”</p>
<b>28</b>	21	<p>“I Um, so two weeks you were... and, and then you, you... they started thinking about discharging [overtalking] to go home.</p> <p>P28 Yeah, so in the third week I actually did go home. I think they do this... I thought it’s a really good idea, actually; they send you home for a day and then they bring you back and they, they see how you were, how you felt, physically... like, well, also they, they take the bloods, all those tests, and then if they’re happy then they’ll let me go home permanently.”</p>

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*4.3.1 Table: Participant discharge time frame*



## 4.4 Post-transplant

Following discharge, most participants had arranged for support and care at home or family and friends stepped in to help. For some who had not arranged for post-transplant care, they noted their amazement at how friends and family stepped up to help them and voiced gratefulness and emotion for their support networks.

Yes. And, um, you know, it was, [pause] it was, er, [pause] something I should have obviously, er, made allowances for, but, I mean, the doctors must have talked to my father and said, look, you know, he can't be alone, he needs to have 24 hour care, and he must have just put his hand up and said, I'll do it, er, you know, I was most grateful to him. Still am, of course.

Participant 16

No it was remarkable, I stayed at home having a 'Cultural Olympics'. My friends were extraordinary. I don't know what I've done S came from Paris, I went to university with him. He left £1000 on the piano! He's not rich, and I found it, and er to keep me going...and P, R kipped over on the couch with Ocado, he is rich but he was a job when I knew him and er at university but um, they paid for the shopping until I, you know...all of it!

I was very, very surprised, you know these people really cared..... It was amazing.

Participant 19

In contrast, there was also a narrative from participant 13 to maintain autonomy and independence, thus to some extent rejecting social support and advice from health professionals to embrace care and support from others and trivialising the medical procedure that they had experienced.

...and if they had known the situation I was going to end up in, looking after myself, I was refusing... my three sisters who have all got excellent jobs in Scotland, but my mother was of more concern, right? You've got enough on your plate there, I'm doing fine. A liver transplant, that's nothing now, kind of thing. It's not a big deal, it was 20 years ago. I'm fine, otherwise they wouldn't have discharged me, attitude.

Participant 13

Follow up care came in the form of the district nurses for wound care and regular appointments with the liver transplant team. Generally follow up care was regarded very well and followed the theme of satisfaction throughout all participant experiences.

Yep. And every, every time I've come up, you know, LS [transplant coordinator] has, sort of, LS has, has grabbed me for a, a quick chat each time, just to say, hi, how you doing, sort of thing. So, you know, it's, it's nice to know that there, there, there is someone here if I do need to talk to someone.

Participant 14

Oh, my goodness, I, I... er, totally so, yes. I mean... and then the district nurses, er, used to come and see me, and they were great as well, you know, so, yeah, it was terrific, yeah.

Participant 16

Um, so district nurses coming, that was helpful, um, dressing the wounds and they were quite funny, some of them. I had a bit of an issue with, with the beginning 'cause they wouldn't come. Yeah.

Participant 22

However the security and the loss of the 'family' feel of support particularly from the ward and being an inpatient was also clearly felt amongst participants. The ongoing physical and emotional challenges of recovery at home would sometimes highlight feelings of isolation, low mood and anxiety.

So everything was going just fine. I, I did get home. Sorry, that's missing, and although you come back to clinic, um, once you've gone, you, you've gone. Nobody 'phones you, um, and [pause] you feel [pause] um, some days you feel really alone and a bit scared, and if you're on your own in the house, and you've got, you know, bits of you are tweaking or in a bit of pain, or something, you, you can get a bit panicky. And yes, you can ring the transplant co-ordinators, um, very... they're doing their jobs, so they're not usually sitting at their desks, um, so you maybe don't get a call back for, for several hours. Um, and I don't mean that as any disrespect to them because they've been absolutely fantastic. They would come round, spend time, you know, and they would... if they were the one that was on call and they were still around, they would come in at ten o'clock at night sometimes, say, that you had a really bad day when I saw you earlier this morning, how are you feeling now? Absolutely fantastic.

Participant 20

Post-transplant experiences were described as a balance between getting on with living a normal life and managing set-backs. For many participants, transplantation was the doorway to getting back to normality, and once discharged they were excited to making steps toward everyday routines and catching up with things they felt they'd missed out on whilst being unwell. Transplantation allowed them to reflect upon how normal life was a blessing. Having been discharged, familiar surroundings and everyday routines also helped with the healing process.

Part of me certainly for the first year, all I wanted to do was catch up on my life.

Participant 1

And, um, you know, to be in familiar surroundings calmed me a lot, and, you know, I could sleep a bit better and, you know, so things... a sense of normality really came back to me.

Participant 16

I'm really looking forward to getting through this first year so that I can be back to what I would consider to be a really, really good state of life, probably that I've not enjoyed for about the last 15, 20 years.

Participant 23

For Participants 22 and 24, normality was also a way of coping before and after the transplant and a form of reassurance for themselves, their family and particularly their children. Both participants, despite their deteriorating health continued to work right up until the transplant date and continued with family and childcare responsibilities. Both were women with young children and being a mother and displaying strength in coping was an important component throughout their illness and the transplant process.

[talking about before the transplant] Yeah, no, no. But except I, except I was really ill. I think, looking back now, I don't... didn't, kind of, keep realising how ill I was during each attack and, kind of, after and each time it took me longer to get over even though I just ploughed on regardless.

Participant 22

P: but that, again, that's how I cope, you know. If I can do something and be as normal as I possibly can, and, you know, it was a big thing for [youngest son] as well, you know, I didn't see him that often when I was in hospital, I didn't see him for at least a month 'cause I wouldn't let him come near me with all my pipes and tubes and...

I: With such a young child, yeah.

P: Yeah, yeah. And, do you know, he's been fantastic, um, but I didn't even want my big boys to see me like that either, so I wouldn't let them come for a few weeks.

I: So, I mean, a lot of it was about also keeping, keeping the face of normality for your family...

P: Yeah.

Participant 24

Normality following the transplant was also described in the form of 'new beginnings' a chance to reassess life and go back to fundamentally enjoying life as a new normal. Adaptations to normality were taken into account, readjusting routines to encompass medication taking and living in a way that would continue to value their health and the new liver.

Because it's just normal life, you know? Because, [pause] because otherwise you, kind of, you know, like, otherwise what was the point of having the liver? You know, I'm not sick, I've just got this, um... [pause] I've been given a gift that I've got to look after really well. Not that I didn't look after my previous liver 'cause it's not...

Participant 22

Um, but no I, I... getting back to normality to me is, is not, as you say quite rightly, it's not going to be the normality I had before the transplant because my life was a, sort of, a completely different mess then. Um, as you say I was, I was going through life almost, I say, with blinkers on, you know. You... I wasn't thinking really laterally at all, it was just, well, I'll get to that point, you know. There were no real major points ahead that I was looking forward to. Um, but I've started applying for, for part-time jobs and things now. Sedentary ones, not, you know, sort of money changing up at the air... because it... there's lots of jobs up at the airport. But... and also it's, it's to do something to occupy myself as well. Although I could spend all day writing a piece of music, but you, sometimes, you just have to feel in the right frame of mind to do it.

Participant 23

No, I... my... instead of the, the days being full of doing nothing, which is what they were before, um, now my time is, is getting filled up. Um, and my wife and I have been away several times now, which we couldn't do before; we've been away in, in this country and we've just started to travel overseas as well and, er, so on, and we've

always enjoyed travelling but now we've enjoyed travelling purely for pleasure instead of, er, business and pleasure. So, er, it's, er... there's a slightly different emphasis in terms of that; a lot more relaxing and so on. And I'm never going back to the high pressure, er, business travel that I used to do.

Participant 25

However, managing post-transplant complications such as rejection and infection often caused set-backs which were both functionally and emotionally challenging. Naturally, some participants experienced worry over the possibility of rejection and the risks of infection. Extra precautions were taken to try to manage these risks.

Well, the CMV<sup>1</sup> was... see, the CMV was seriously, er, holding me back, 'cause I was getting out clear, then I'd get a phone call after two weeks, right, it's back again, right? So I'd go back on the tablets again, so because of what I'd been told upstairs I wasn't getting any sight of... I wasn't getting any effects of this illness whatsoever, but I was aware of the potential what it could be if it took a grip. So that's... I was, I was accepting that, and I, I suppose I was getting a bit, kind of, depressed 'cause I'd passed the three months mark, and it was all down to this CMV, er, that was... as far as I was concerned that was hindering

Participant 13

I still get pain from the wound in movement and so on, but, you know, nothing I can't deal with really. I didn't take any of the painkillers I was given, er, [pause] because, er, I knew that rejection... one couldn't actually feel rejection and that worried me. I wondered if it was to do with the, the painkillers that one was given. I know now that that wasn't the case but, you know, at the time I thought, well, I'd quite like to know. And so, you know, it, it's funny how your mind works in strange ways.

Participant 16

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<sup>1</sup> Cytomegalovirus (CMV) most common viral infection in solid organ transplant recipients

My donor was CMV positive and I was CMV negative, and they said to me, at some point you will have to cope with CMV arriving in your body. Um, when I was initially discharged after the transplant, um, they gave me the drugs to take and said, the moment you have a blood test and it gives a reading, um, we will let you know, and you start taking them. So it did, and they did 'phone me and say, start taking them. Um, unfortunately I reacted to those - the valganciclovir - reacted to that drug in that I stopped producing red blood cells, um, so my haemoglobin was tumbling, um, and it was just getting me in a bit of a mess. So I came in, had some blood transfusions, um, and some other things to boost me up, and, um [pause] then they gave me some... well, what they said is, they, they wanted to give me something else but they just wanted to see how I went for a few days, because I was in... I stayed in for about two or three days, I think. Went home over the weekend but my temperature was going up and up and up, until on one Monday night it was 39 so the only place I was going to be the next day was in here. So I came in and then I was in for four, five weeks, something like that, um, and the CMV had just got really, really bad, so it had to be treated intravenously

Participant 20

It wasn't just the medical side of things, everyday physical and mental challenges were often very difficult to manage but many participants found ways to cope to optimise daily living as much as possible.

And it wasn't, it wasn't just the physical side of things and I knew obviously there are going to be physical difficulties, um, inevitably. But, but, you know, yeah, it was the mental side of things.

Yeah. Um [pause] probably the just getting so tired physically so quickly still. You know, so, so... you know, sort of feeling useless at times if that makes sense. You know, you, you'd want to do something and you just hadn't got the energy to do it.

Um, and, you know, and then, sort of, you know, your mental frustration that comes out of that, you know, I mean, I, I want to be doing this, I want to be playing with the kids but I just can't do it, I haven't got the energy, you know. And, and my sister's got four, four young children who are, you know, are fantastic, love spending time with them and obviously, you know, just have, having to sort of sit back and not be able to, to play with them.

Participant 14

Well, some little things, like you think, I'll order something from Amazon, er, there's a book I've been wanting to read.... but, you order something from Amazon, delivery people don't wait around while you struggle off the settee to try and get to the door. So then you've got another problem, um, so the easy thing to do is put a note on the door, or get someone to put a note on the door, um, you know, you don't have to go into great specifics; I've just had a, a big operation, I will get to the door but please give me a bit of time.

Participant 20

Um, [pause] the, um... it was really hard having a, a 12 month old baby because I couldn't carry him. Couldn't lift him or carry him 'cause I couldn't get him out of the bed, um, put him in his cot, well... and also just him... you know, they are at that stage where they're standing up and crawl... you know, climbing over you and stuff like that. So I had to learn to do things different, you know, differently, so I'd always hold a pillow over my tummy area so that he could still cuddle me but not push against anything there 'cause that was... and that took quite a few months really.

Participant 22

Previous investigations into the quality of life in transplant recipients have focused on the relations between medical treatment and transplantation (Dew et al 1996; Jacobsen et al 1998). Yet Nickel et al 2002, have highlighted emotional aspects (depression, coping and



anxiety) as well as how aspects of the social environment can contribute considerably to determining the well-being and health-related quality of life following liver transplantation. This sections exploration of the phenomenon of having a liver transplant has further highlighted the importance of the psychological and emotional factors that can impact a participant's journey through from diagnosis, transplantation to recovery. However, unable to abstract itself from time, place and from the individual, this inhibits continued analysis and the development of a core concept to determine the process of adapting. The next section will continue in detailing a second phase of analysis. Through exploring participants experiential journeys, what has also been highlighted is that participants willing to be part of this study all described liver transplantation as a positive experience. This will be further explored in the next section through questioning "What is it that enables these participants to live positively following the life-threatening and altering procedure of having a liver transplant?"

## CHAPTER 5: EMERGING PROTECTIVE FACTORS

### 5.0 PROTECTIVE FACTORS

The concept of 'protective factors' has grown to be an established field in psychiatric risk research and developmental psychopathology in the last decade (Garmenzy, 1985; Masten and Garmenzy, 1985; Rutter, 1979; Rutter, 1985). Its roots are in the notion of resilience, resilience being the ability to bounce back from adversity and evoking the promise of something good resulting from misfortune (Dyer and McGuinness, 1996). This is a shift from focusing on vulnerabilities and risk variables to looking at the process of negotiating risk situations (Rutter, 1987). Garmenzy (1985), reviewing stress resistant children concluded that three broad variables encompassed protective features 1) Personality features such as self-esteem; 2) Family cohesion; 3) the availability of external support systems that encourage and reinforce a child's coping efforts. Southwick and Charney (2012) through their research interviewing a range of individuals after having experienced severe traumatic psychological traumas identified 10 protective coping mechanisms that proved to be effective in managing stress and trauma; realistic optimism, facing fear, moral compass, religion and spirituality, social support, role models, physical fitness, brain fitness, cognitive and emotional flexibility, and meaning and purpose. It is through interviews with patients who have received a liver transplant that these 10 protective factors will be discussed. As Southwick and Charney stress, this list is by no means definitive or complete. Additionally for the purpose of this research study, you may find that some issues that arise from the interviews also overlap in categories of protective factors.

#### 5.1 Realistic Optimism

Optimism is defined as a hope or confidence about the future, a future-orientated positive attitude. Taylor (1998) identified two styles of optimism; dispositional optimism (also

trait optimism), this form of optimism tends to be stable from one situation to another; and situational optimism, in which an individual may expect a positive outcome in one situation but not necessarily in another situation. In this study interviews focus on the circumstances surrounding having a liver transplant and thus interviews can only gauge some understanding of individuals' situational optimism under similar experiences. However, some participants do indicate to a predisposition towards being optimistic.

Oh, I don't know. Um, no, I think, I think the drive is positive. I, I, I, I, I don't see anything negative about it. Um, I, I, I've always been probably an optimistic person and an outgoing person and, er, er, and positive. That, that's, that's my nature, sort of thing. Um, and if somebody said, is that glass half full or half empty I was always the half full.

Participant 25

Optimism as a protective coping strategy is not, however, blind. For building resilience, optimism does not discount all negative in life, rather, it pays close attention to relevant negative information and does not remain focused solely on the negativity (Reivich and Shatte, 2003). If problems appear unsolvable realistic optimists tend to disengage. The following participant's provide examples:

Um...no, afterwards, it was over. It was over so quickly. I just got over it and...no, I knew, once I woke up, I was fine. I never ever doubted that anything would go wrong. I don't know why coz it could have done I suppose. I honestly never worried after the transplant, I thought 'that's it'. And I do now, my friends say to me now...coz I think they said something like... 'Oh, If it doesn't come back in 5 years...' 'What you talking about in 5 years?! I've got a lot longer than 5 years!' You know? And people say, 'Oh do you worry about it coming back?' 'No! It's not coming back!' and if it does, what

can I do about it so I'm not going to worry about it. But I don't, it's not! Not for a long time.

Participant 1

Yes. Yes, very much. Try, trying to be positive in, in the way I'm moving forward. [Pause] And that's what I was trying to demonstrate; well, okay, it might be a problem, but you can beat it, you can get over it, and, and it shouldn't hold you back in the future.

Participant 14

Yeah, I do, yeah. Yeah. 'Cause it... you know I said to you... I mean, I have no idea how long the liver's going to last, no-one does. My test results are really positive so that's really good and I, kind of, think, you know, there's a... what is it, um, [unclear] 85% of people get first year, no problems. I think, er, you know, well, if you look at the statistics nationally or whatever else, so, er, I'm, like, good. You know, it's the same as, I could actually get this disease... there's a 40% chance that I could... the disease could rear its ugly head again in the new liver and bile ducts and I'm, like, yeah, but there's 60% chance that it won't; I'm going with the 60 thanks. You know, kind of, glass half full I reckon. And that might be because I've got kids, I don't know.

Participant 22

For each of the excerpts indicated above, participants acknowledge that there may be potential problems ahead and that transplants do not last forever. As much as individuals can do their best to take care of their transplant (good adherence to medication, alcohol abstinence, self-care etc), there is a recognition that there is a lot about their health and their transplants that they have no control over and an acceptance of this fact. Thus for issues that cannot immediately be resolved there was a recognition that the best way to cope was to move forward, and deal with what was presented at that moment in time.

## 5.2 Facing fear

Southwick and Charney (2012) discuss the importance of ‘extinguishing’ neurologically conditioned fear through using techniques such as ‘flooding’ or exposure therapy’ requiring prolonged exposure to the memory of the traumatic event. However in the case of experiencing the process from diagnosis through transplant to recovery, trauma or adverse events are constantly changing phenomenon over the course of a number of years. Techniques such as ‘flooding’ or ‘exposure’ are less relevant when there is a lack of a tangible object that is feared. Instead fear in transplantation may be more abstract concepts of ‘life and death’ (Beard, 1969). A recurring theme from participants was the reflections on death and dying.

Um, I went through a number of stages. There was a period when I was really scared I was going to die

Participant 20

The reality was that the transplant operation itself was a huge risk that participants had chosen to take.

...at that point I was committed to it, there wasn’t a lot I can... you know, oh, well, I suppose I could have backed out at the last minute but, you know, I, I think at the back of my mind I knew, if I didn’t have it, that I was a gonner, so, you know, I, I had, you know... it was my best chance of survival so I had, you know, I had to take, I had to take that chance

Participant 14

Um, [talking about a fellow patient] and then they said to him, look, you’ve damaged your kidneys as well, so much, um, you’re not going to make it through the operation. So, um, his... I’m sure the consultant didn’t say this, but his phrase to me was, they, they told me to go home, get my affairs sorted out, but don’t bother buying a diary for next year. And of the four of us that were in that bay, I mean, two are dead now, and

that's only, like, six months on, six, seven months on. Um, and that was a really stark realisation of, of how serious... of, of just how serious the situation was

Participant 20

There is value in treating conditioned fears that may arise from the transplant process and recovery. Indeed traumatic experiences such as Participant 16's experiences with anaesthesia during the operation ("But, um, I was just filled with terror nightmares of the most extraordinary, I mean, horrific type. I mean, it was just... when you say nightmare you can't imagine what nightmares can be, I mean, it was totally a horror story like you can't imagine." – Participant 16) could potentially cause a phobia of being put under anaesthetic in the future. However a more relevant issue to acknowledge about fear is that fear is inevitable and, at times, everyone feels afraid. This is reflected in the participants' discussions and thoughts on death. Where some participants like participant 1, challenged or questioned death:

And in fact I did use to...some days...um...just to check out whether I was going to die or not I would go on my horse to a beautiful place called SP, it's massive, miles and miles of nothingness...and I would take my horse out and I would take my riding hat off and I would just gallop and I used to think "If you want me, take me now! don't lets do all that silly hospital stuff, Here I am...I'll fall off...if you want me, do it now!" and I never did.. So every time I did that, when I needed me to do it, it was my way of...and I thought "that's it, I'm going to be fine"

Participant 1

Absolutely. It wasn't the right time to go. But that was personally a thing I could do, it didn't involve upsetting anybody else. My horses didn't care. So I was very lucky I had that and I would do that regularly and go "...I wonder if it's today?" and it wasn't

Participant 1

Others also accepted deaths' role in life and as part of their journey in life:

No, no, no. I didn't feel any of those things. Um, it was just... I just, you know, took it on as a matter of fact thing and got on with it as best I could.

Participant 16

No, it was my attitude right from the beginning 'oh well, I don't feel I've finished yet, but if I have to go I go. And no, my mum particularly couldn't understand it and I said there's absolutely no point in pondering whether I would die.

Participant 19

Others spent time in 'serene reflection' of death and dying. Participant 19 shared his experience of being 'in the moment' watching the world from a slightly distanced but peaceful place.

I remember the second ambulance taking me and I was thinking, 'well, this is probably it' and I was being all bouncy for M my daughter and er, I looked out on the street, waiting for the ambulance, I took a photograph of it and thought 'well, this might be the last time, I see this street' and it was just matter of fact, and there were 2 friends of mine leaving 'The C' which is a pub on the canal just at the end of my street and I was in the ambulance, we were waiting at the traffic lights and I thought 'shall I?' and then I thought, no, it would take too much explaining, and they were in deep thought and they were obviously, it was midnight, so they were the last people in the pub and they were just chatting and they walked straight past the ambulance and I watched them walk past Lime street. And um, it was a very serene feeling. I wasn't in any way concerned, I'm sure...I 've had other people diagnosed with cancer and it's awful, but...but...for other people, but for me it wasn't.

Participant 19

The idea of facing fear as a protective coping strategy may be whether an individual is

able to face it, to reflect and think about it in the first place. In this case, fear then does not become an object to be 'afraid' or avoided but a part of circumstances. In Southwick and Charney (2012) research on resilience, they suggest not allowing 'fear hang around for too long'. Through a process of challenging, accepting or reflecting on death, for example, participants may be more able to confront fear and overcome the challenges of their anxieties.

Furthermore, in a situation such as a high risk transplant operation participants might feel they are permitted to feel fear. Thus there is a level of acceptance that although there may be some irrationality behind their fear, there is also reality behind what they are feeling...

I'm nervous that someone's going to hurt me. Um, if somebody, if somebody were to knock me over, goodness knows what I'd do, because I wouldn't want anybody just randomly pulling me up, um, because again you just don't know what that might do. Maybe that's, maybe that's an irrational fear of mine, um, but irrational or not, it's there.

Participant 20

...and some curiousness when fear is not felt:

I: And you've said that you had a strong feeling and attitude, and also the consultants and Drs have said that, that, even how you were before and leading up to the transplant your attitude to things really kind of made a difference.

P: I think so.

I: What do you think was the main difference between you and other people?

P: A lack of fear, comple...I, I was really puzzled really,

Participant 19

### **5.3 Receiving a gift, altruism and giving back**

Receiving a transplant is unique in that the individual receiving a transplant requires another individual, (the donor) to have made a prior decision to provide the liver - an act of



altruism. Majority of participants for this study received a transplant from a cadaveric donor (i.e. one who had previously decided to donate organs and had since passed away enabling the donation of a liver). This act of selflessness and concern for the welfare of others from the donor appeared to have a great impact amongst those interviewed.

For those who required transplantation due to alcohol or substance misuse many viewed it as a 'second chance'.

Yeah, I, I think it's that, that sudden realisation that, actually, you're getting a second chance that a lot of people don't get. You know, it's... I, I've all but thrown it away now, well, hang on a minute, I'm getting a second chance to put it right

Participant 14

Well, I, you know, it was... I was very glad to, to get the call and, you know, have a, have a chance. You know, I knew that it was, er, it was something, er, you know, gift from god if you like. So I was most grateful to get the call. Very pleased to get it.

Participant 16

Others, acknowledge the gift and reflect on the sacrifices that have made to provide the transplant opportunity.

Yeah. Well, I, I have been given a gift, you know, and I... the person who died, the woman who died, her family lost her, but I, kind of, you know, I gained from her death which sounds awful but it's true. But I know... the thing is, I do know she, she was going to die, or she did die, that, that wasn't going to be stopped. So, um, she did a very selfless thing, you know, by putting her organs forward, so. And they said to me... what I loved is Dr said I got a Rolls Royce of a liver not a Ford! So, yeah.

Participant 22

Additionally several participants disclosed their gratefulness to the NHS and the skilled professionals that cared for them throughout their transplant journey.

Yes because everybody has their job, it was the team work. But I found the Liver specialist nurses were wonderful. As barmy as some of the ideas I came up with, they listened, they checked things out for me and they got back to me when they said they would. Because there's nothing worse than you sitting their worried and with a concern and there's nobody to talk to.

Participant 1

so I remind myself of that every day. So it's no... I'm, I'm, I'm grateful, I was grateful to be British and be in a, in a system where I didn't have to go through the, the, the worry of, ah, having to finance the... myself and things like that, yeah?

Participant 13

It was... until, until October when I first came here and saw Dr P I wasn't really sure what was wrong with me. I'd had some months of not knowing and all of a sudden I was amongst expertise that just fills you with confidence. Um, I mean, I couldn't, couldn't praise the medical care I've had here enough. It's been absolutely fantastic, um, and so, yes, I had the transplant on Saturday.

Participant 20

He was amazing, yeah. Um, all the surgeons, everybody, there's the whole team, you know, I know it's not one person, I know it's a whole team of them, and that includes, like, lovely, R on the ward who does the breakfasts, um, you know, the people cleaning, it's everyone. I mean, [hospital ward] is quite a remarkable ward, it really is. Um, you know, and I watched them have to look after some quite challenging patients over the time, in and out, that I've been at, I have been here a few times. But, um, yeah, so I was, I was, [pause] yeah, I was really lucky, yeah.

Participant 22

Yeah, and the reality... You know, somebody has spent thousands and thousands of pounds giving you a new liver and 18 people in theatre have done the most amazing thing.

Participant 23

Yeah. I, I, I think that... I, I don't know about other centres, er, but certainly here, um, I have got nothing but praise for the, the doctors and, with the exception of one nurse, all the nursing staff. Er, they, they've all more than gone out of their way

Participant 25

Schwartz, Meisenhelder, Ma and Reed (2003) found that positive mental health was most common among church members who either helped others or received help from others. Furthermore, providing help appeared to be even more strongly associated to positive mental health than receiving help. Similar findings from Schwatz and Sendor (1999) reported that individuals with Multiple Sclerosis who were trained to provide peer support to fellow patients also experienced improvements in their personal wellbeing. Schwartz (2003) followed this research into altruism further to find its association with better life adjustment, marital adjustment and reduced hopelessness and depression. Her team further found that social interest moderated life stress and predicted physical health status. A shift in the attention from oneself to others could possibly enhance self-confidence, self-acceptance whilst also reframing one's own illness experience through a greater perceived meaning in life (Schwartz, 2003). Although there is no formal peer support system, many participants were keen to provide others with support, either by providing advice or by publishing written work of their own experiences.

I am supporting 2 other people going through liver transplants

But after, you know I am so grateful, if I can do anything to help.

Participant 1

I've had my lottery win, I said, I'm quite happy with life and, er, that's it, and if anybody can learn anything from it, I hope, I hope they can, so.

Participant 13

[regarding alcoholism] ... and, and it's made me realise that, you know, well, maybe if I've been through this and it was bad for me well, can I turn that into something good, into helping other people, which is where the work with the charity is, is coming in. You know, can I help other people learn from what I got wrong?

Participant 14

I have, that's... and that's my aim, is to put something together that isn't too unwieldy, so it's readable easily, um, and yes, and it can just be shared with people. I don't think... wouldn't do it as a... I'd only do it as a money making exercise if it was going to raise money for some related charity.

Participant 20

And they, and they had... were at the start of that and they'd had some of the symptoms that I had and they were confused by it, and I was able to, to share my experience with them which was... which... they actually helped... it helped them in terms of, er... where they were, oh, I've, you know... and I've had that, and what did you do? And, and so on, and that sort of thing so that was helpful.

Participant 25

Some participants found themselves in the position of wanting to be of help to specific individuals even whilst on the ward demonstrating moral compass not only as a result of having a liver transplant but through empathy for others in similar positions who they want to succeed and encourage to wellness. The camaraderie and support on the ward additionally encouraged patients to morally support each other's progression and needs.

If I can help somebody, I will. So I found it, for some reason, relatively easy and pain-free to struggle to go to toilet, I was just concerned I was going to rip some of these

bags out. But, but this bad dream where I'd seen the geezer, thinking his face was covered in ice, I was determined that he wasn't going to die, and there were a smashing family of Jamaicans who would sit there on his bed every night, and then, er, I probably imagined the fact that they'd said to him, well, he can do it, why can't you do it, kind of thing.

Participant 13

Yeah, she was about a month... she, I know, 'cause she had it on [unclear] night, um, Guy Fawkes night. Yeah, so she's, er, sort of, a month ahead of me. But in a different place, completely. I know she's young, you know, and she's got other health... you know, she has got diabetes and she's... but, um, yeah. Her Mum and Dad are lovely, um, and I... but I've also suggested to her that she could, er, join... 'cause she's got the same disease, you know, join some Facebook thing and does this, and she's just not very, um...

Participant 22

## 5.4 Religion and Spirituality

Southwick and Charney (2012) argue that the relationship between religion, spiritual faith and resilience is well supported by scientific research. In a meta-analysis looking at 42 separate published studies, McCullough, Hoyt, Larson, Koenig, & Thoresen (2000) found that people who actively practiced a religious faith lived slightly longer than those who did not. Powell, Shahabi, & Thoresen (2003) also suggests that patients with rheumatoid arthritis, severe burns and organ transplants who consider themselves to be religious tend to see themselves as healthier, requiring shorter hospital stays and fewer medical complications than those who describe themselves as not religious.

Within this study's interviews with liver transplant patients 2 types of spirituality and/or religious coping appeared to occur. Firstly faith and spirituality to help the participant

get through the challenges of the transplant process:

This is what I've learnt through this experience, because I have listened to a lot of spiritual people about how we live our lives and it all comes back down to being in the present.

Participant 1

I think so but it, it... I, yeah, in a way I hope that, er... I've got great faith in nature just finding its own way and I think this is one of those things which is... it'll find some way in, in its own time, yeah.

Participant 16

Um, perhaps it was my faith that I was... which held [or helped?] me as far as that was concerned. I wasn't... I'm not afraid to die.

Participant 25

So it's god saying to us that if we put our 100% complete faith in him then he will look after all the physical... everything, basically, everything else. And I just remember thinking at the time that, you know what, like, yeah, I do have a family, husband, friends, all of that, but at this moment in time, like, you know... they've done everything they can but now it's just in your hands, there's nothing now... you know, I'm going into theatre, um, it's just whatever you do through these doctors and nurses, um, and that's fine, what, whatever you decide; whether I come out or not, um, I'm happy with that.

Participant 28

As indicated by these quotes, not all participants found faith in a specific God. Participant 1 found coping through learning about many spiritual ideas, whereas participant 16 found faith in nature's course. Participant 25 and 28 both discussed their active engagement in their religious community and hence their faith in their religious God.

A second type of coping through spirituality and religion was as a form of seeking healing and recovery. Participant 1 was keen to use alternative remedies to optimise her health as much as possible. This was not always agreeable with the medical doctors and sometimes required negotiation with them.

I've always been interested in spirituality and the unknown and alternative things, because that's what I do with my horses. I buy sick horses for £1 and I get them well. I very rarely use a conventional vet. I use homeopathy, I use aromatherapy, I use nature.

Participant 1

Participants 16 and 19 turned to breathing techniques or forms of meditation to cope with the long days in hospital, pain or side effects from the operation or medication.

P: I spent, [pause] er, most of the time... I, because I couldn't sleep, was just meditating. I spent a long time, you know...

I: Do you do, do you do much meditating? Meditation?

P: Well, I, I, I used to study it when I was in Japan, you know, so I did it for ten years, so. [Pause] And it came back and was very useful.

I: Yeah. In what way?

P: Well, I was able to control my breathing and, for a short while, I was able to, ah, escape the horrors, you know, and, er, get out of the hospital, so to speak.

I: Yeah, so that was whilst you were in hospital, you would meditate a bit [overtalking].

P: Yes. And when I was out as well, yes, I continued.

Participant 16

That felt like a kind of, whatever it is, meditation. I'd find that 5 hours had past, at the beginning, the night dragged on forever. And then after about a week of this, I'd look at the clock and go 'my god it's 5!' and I hadn't been asleep as far as I knew. And I felt

like a real cheat, being able to just sit there and somehow, be able to achieve some sort of, not unconsciousness but some kind of...whatever, time just went. I don't know how meditation can do that.

Participant 19

It is not completely understood why religion is positively associated with positive physical and mental health as well as resilience (Southwick & Charney, 2012). However there are key components of being spiritual and/or religious that might foster resilience factors. For example being engaged in religious communities similar to how Participant 25 and 28 were. This provides the social support within which there may be positive resilient role models. Such religious groups may seek a focus on altruism and a search for meaning and purpose, each enabling and strengthening resilience.

## 5.5 Social Support and Networks

High quality social support can enhance resilience to stress, help protect against developing trauma-related psychopathology, help manage and decrease the consequences of post-traumatic stress disorder (PTSD) and reduce medical morbidity and mortality (Southwick, Vythilingan & Charney, 2005). High levels of social support can significantly impact the likelihood of developing clinical depression for patients with cancer (Manne, Pape, Taylor, & Dougherty, 1999), cardiac illness (Holahan, Moos, Holahan, & Brennan, 1995), rheumatoid arthritis (Revenson, Schiaffino, Majerovitz, & Gibofsky, 1991) or multiple sclerosis (Mohr, Classen, & Barrera, 2004). And that isolation can also affect our physical health, for example Rozanski, Blumenthal, & Kaplan (1999) found that a small social network or inadequate emotional support is associated with a threefold increase in subsequent cardiac events among patients who have previously had a heart attack and a two to threefold increase in future coronary artery disease among healthy patients. Salpolsky (2004) even suggests that the effects may be as strong as the effects of obesity, smoking, hypertension or level of physical



activity. Holahan et al (1995) further suggests that rich social networks can enhance mental and physical health by fostering effective coping strategies, increasing self-worth and reducing the perception that problems and dangers are impossible to overcome. Neurobiological research suggests that social support may moderate genetic and environmental vulnerabilities enabling resilience to stress via the impact on the hypothalamic-pituitary-adrenocortical (HPA) system (Ozbay et al 2007).

Within the interviews for this study, there were a number of individuals who already had a strong network of friends and family to draw support from. These individuals also tended to seek support from other sources such as health professionals or online/social support networks, thus demonstrating an ability to seek and gain support from others easily. A couple of others felt too burdensome to ask for support or felt they did not need or want support from others. Overall a wide range of sources of support were discussed in interviews. The table below draws examples from each type of support.

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**Type of support**

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**Family and friends – For participants interviewed, family support was either essential or to be avoided. There were diverse opinions, where some individuals found it important to share their experience with their loved ones, knowing that family would help them not only get through the practicalities of being unwell but also that emotional support was essential. Others found disclosing their illness to family was either pointless because they weren't close or it would be burdensome and considered their friend more as family.**

“I felt very sorry for people who, um, don't have support, don't have family, or are so sick that they are not well enough to fight for what needs to be done and I was lucky coz I felt well.” Participant 1

I: Mm. A lot of people find... well, some people find it very helpful to have friends and family around.

P: I know, yeah.

I: For that support.

P: Ah, yes, that's just what I didn't want.

I: It's what you didn't want?

P: Yeah.

I: And why's that?

P: Well, I, I couldn't... I can't bear people's, sort of, pity and, you know, to have to drink all that bloody herbal tea when, really, you're... you know.

I: Okay. So it was trying to avoid the fuss that it would create?

P: Yes, yep. Yeah.” Participant 16

“...My family is a bit...of course my mother, my dad's dead, my sister was very good, although that's sometimes a poor relationship but she was really good. My brother is an alcoholic so, he came down, was surprised at how well I looked and went back up. Erm...My friends, I'd decided a long time ago were my family, coz I didn't have one really.” Participant 19

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“I had people around me, I had my son around and my daughter around me, girlfriend with me, friends popping in all the time, um, which was good.” Participant 20

“The most support I got from my first wife, my... and with my eldest daughter, um, and... I didn’t really tell many people, not because of shame or embarrassment, but I didn’t want, you know... ‘cause people kept saying, ooh, well, let me know if you want this, or let me know if you want that, and I didn’t want to be like that, if you see what I mean. I wanted to be myself and to... just carry on and do things.” Participant 23

“And then of course there was a lot of my long-standing church friends... not just in the local church but in a much wider context because, um, I, I got quite a, a large number of contacts and friends, um, spread around the world and, er, they were, um, very supportive, um, praying for me and so on. There were people in America who were praying for me, people in the Far East, people in, er, er, Canada and so on. In fact, I had visits from, um, people in Canada, came over specifically to see me, so, um, you know, there was a lot of that sort of thing and, er, friends in Australia and so on, so, er, yeah.” Participant 25

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**Peer - Participants sought to connect with other patients who had previously experienced a transplant. They also wanted to provide support for others in similar situations with a sense of altruism (as discussed above in *Receiving a gift, Altruism and Giving back*) but also possibly because of the value they see in having good support from others who have had shared experiences. Brown et al (2003) reported how mortality was significantly reduced for older adults who provided support such as material goods, services or financial support, to friends, neighbours and relatives.**

“And she gave me a name of a man in France actually who’s English actually but he moved to France with his family because they wouldn’t do a transplant in England, so he moved lock stock and barrel to France where he then finally got them to do it in France. He was then, he told me, off skiing with his twin boys and he’d had his 3 years previously. A total stranger, never met before but just being able to talk to him in a different way that you talk to Dr’s. He was fantastic, absolutely fantastic.”

“so I um, honestly felt having people who had been through it was the best thing ever.” Participant 1

P: No, it isn’t. It, it’s so fast so my, you know... I, I joined a Facebook account for PSC, um, people with PSC disease, and I joined it when I had the disease, so when I was, sort of, diagnosed I was, kind of, looking around, so I joined... there’s, er, like, an online... there’s a newsletter that comes out through the PSC support group – that’s the website. Then I thought... then I joined the Facebook account with them as well, um, and they advertise things like, um, like, in... there was a, um, in March or February, there was a, that thing in Birmingham for people with PSC...

I: I... yeah, like a conference.

P: Like a conference, yeah, so it’s been really helpful knowing things like that, but equally hearing other people’s stories from, um, transplant or other people who haven’t got transplant but have got loads of other problems, like...”  
Participant 22

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**On the ward – The camaraderie on the ward (as discussed in section 1: *As an inpatient*) provided a large amount of support from those with shared experiences.**

“And then I was moved into another room, um, and I got really friendly with the women in there, um, and so we were... actually there was, there was three of us, ‘cause there’s four beds in a, a ward, um, and, and one bed, you know, we had a turnover of patient but at one point we got really quite, um, sort of, er, territorial, we were terrible! ‘Cause we were together, sort of, three or four weeks and that’s an awful long time so, um, it was, you know, they wanted to move one of us at one point; it was, like, no, we’re all staying together, because we just used to sit and chat, and, you know, you, you do... it’s, it’s odd when you’re in hospital, you do talk to people, um, and they know all sorts... you tell them about all sorts of things that you would never tell anybody else that you meet, sort of, anywhere else after, you know, sort of, straight off... um, so, yeah, we did have some giggles as well.” Participant 24

“I found the sense of spirit and team, the whole community of the transplant ward is really brilliant and when you meet someone afterwards a couple of times have been distressing because they'd deteriorated badly in one case, the cancer had come back. You know you talk to them and go "how are you doing".. "oh, I got an infection and had to come back" "oh really?" and you're all trading stories and again you sort of talk about your experience on the ward "Oh I don't like it" Someone didn't like the one who operated on me because they couldn't understand him.” Participant 19

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**Health Care Professionals – The support and information that was provided from health care professionals was highly valued as discussed earlier in the section under *Receiving a gift, Altruism and Giving back***

P: Yeah. Yeah. Yeah, which is where the transplant co-ordinator at the time..... was really, really helpful. She was great, you know, she, she'd sit down and talk to me for ages if I needed to.

I: Yeah.

P: Which, yeah, which was really good, 'cause you really needed that. And two or three of the nursing staff I got on really well with and they, they were quite happy to, you know, whilst they were doing their rounds they'd, sort of, come... wander over and chat and natter with the... which, which is, you know, a great way of doing it; it makes you feel much more at ease." Participant 14

"No, I thought they, in general, most, most of them have been very, very good, very helpful. They, they've been very knowledgeable and able to put my mind at rest on a lot of things because both my wife and I phoned up, er, and had queries and questions, er, which they've answered or they've passed on to the doctors and so on, and then come back to us and so on. I, I think it's an extremely essential part of the service." Participant 25

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### *5.5.1 Table: Types of support*

## 5.6 Role Models and Learning

Werner, observed that resilient children tended to have at least one person in their lives who supported them and served as a role model (Werner, 1993; Werner and Smith, 1992). Role modelling itself largely depends on learning. To be more specific, role modelling is dependent on observational learning i.e. through watching what someone else is doing (Southwick & Charney, 2012). Bandura (1977, 1986) suggested that modelling was more than simple mimicry or imitation and that it involved learning a set of rules for behaviour which further served as a guide for future action. This involved thoughts, values, behaviours and emotional reactions fitting the particular circumstances of the learner. Although the term 'role model' suggests that it should be a familiar person that is to be admired and one to emulate, as highlighted by Bandura, modelling is merely a form of learning and thus we may learn from those who are familiar with us, whom we admire but we can also learn from individuals in how 'not to act' (Southwick & Charney, 2012).

Throughout the interviews, individuals spoke of learning that occurred in the process of receiving a transplant. At times, comparisons' with others served as a guide for individuals to feel confident of what they could achieve in their recovery. Using peers as role models and to benchmark achievements in progress.

He was back at work after three months, so I'm thinking, well, if you can do it, I can do it, kind of thing, yeah?

Participant 13

And, you know, I [pause]... when I look around to... my fellow transplantees at the, at the, er, clinic, you know, a lot of those people are very unwell. I mean, one of my friends from the ward, I mean, he's... he hasn't made a recovery like I have. I've just been lucky.

Participant 16

Um, same as last time I came, I came to clinic. I was sitting next to a lady who was 15 years out of transplant. Now how do... how good does that make me feel? And she looked absolutely fantastic, and she was nearly 70.

Participant 20

Others have learnt through other forms of support that they have sought throughout the healing process.

This is what I've learnt through this experience, because I have listened to a lot of spiritual people about how we live our lives and it all comes back down to being in the present.

Participant 1

Or from being carers of other family members who have been chronically unwell in the past:

I just think because it is, it is, it is such a big thing and, as I've never been really seriously ill before, you know, if I hinder that recovery then it's just, um, you know... if I'm going to push myself then I'm going to be sick for longer. You know, it, it's... um, and I, you know, I've been my mother's carer, you know, for, you know, four, five years now, and so I can see the signs in her and how she recovers, um, from major operations, and, you know, you know and you learn that you just have to go with it, and you know what you can do when you can do it.

Participant 24

## **5.7 Physical Fitness and Strengthening in Recovery**

Focusing on the benefits of exercise is a valuable vehicle for improving physical and mental hardiness and self-esteem (Gould, 2000). A 2008 report from the Physical Activity Guidelines for Americans, found strong evidence that physical activity in adults lowered risk of early death; stroke; type II diabetes; high blood pressure; adverse lipid profile; metabolic



syndrome and colon and breast cancer. Furthermore Blumenthal et al (1999) found that aerobic exercise was as effective in lowering symptoms of depression in middle aged men as those treated with 16 weeks of an antidepressant (Zoloft). Many more studies have similarly found exercise as substantially effective in reducing symptoms of mild to moderate depression (Barbour et al, 2007). In patients who have experienced a liver transplant, gaining physical fitness is all part of the recovery process. Having the motivation to build strength and recover is, however, not always as easy and can encompass a combination of self-care, goal setting and the ability to push oneself to achieve more within their 'strengthening' routine.

The first challenge in building physical fitness and in recovery following the transplant was the initial mobilising (see also section 1 '*As an inpatient*')

I was determined to get up. I was determined to get up and about as soon as I possibly could, but I remember on the, er, one of the early occasions, um, I tried to get out of bed; my son was there and my wife and, er, my son's wife were there, and I tried to go out into the corridor and my legs wouldn't hold up... hold me up...[...]... I kept on at it and was up... 'cause I didn't want to stay in bed, I wanted to get up and sit up in the chair and get out, um, 'cause I, I was aware that the sooner I could get myself mobile the better. [Pause] But it wasn't all plain sailing; there was one day which I, I couldn't, I couldn't get out of bed.

Participant 25

From then onwards goal setting was important to set up and continue a routine for building physical fitness and a return to health:

Yes. Um, and then there were other things, so starting to walk first of all to get to the door... well, into the toilet, then to get to the doorway, and then to get to the doorway of the next bay and, and setting that... those little things all the time. And the physiotherapist came round every day and would say, how far have you got? And I've

said, I've got to there, um, and then I've though, right, when my girlfriend comes up, I'm going to get to the lift, and it was just constantly like that

Participant 20

However recovery and building physical fitness is also about knowing ones physical limitations and pacing oneself. Setting tasks that are unachievable is unlikely to help foster a routine of fitness and particularly in the case of those recovering following an operation; doing too much can often be counter-productive. Several participants also recognised their limitations and learning about how far they could push themselves, which they described as part of their recovery.

The key to it, I've found out is, if, when you start walking, don't start too fast. Because if you start too fast you, you kind of blow yourself out. It's like the hare and the tortoise, you, you go off at a rate and before you know it you, you're in trouble. Um [pause] and, and you have to suddenly build it into yourself, an element of boldness that says, I'm sorry, can you slow down? Because I can't walk at that pace. You know, I may not look ill, but I've still go some way to... and, you know, I've still got a tube coming out of my abdomen. I've still got a wound that's trying to clear up.

Participant 20

so even, you know, so initially the... just walking... I remember on Christmas Day I walked around the square where I live 'cause I was [unclear] I'm going to do it, and I did it. [Unclear]. You know, but two days later I walked to the top of the road and back so I was, kind of, walking that little bit further every day but forgetting sometimes... one day I did walk too far and realised, shit, I've got to get back!

Participant 22

Where Southwick and Charney (2012) are discussing the benefits of physical training and exercise, intense physical exercise was impossible at the stage of recovery discussed with the interviewed liver transplant patients. In this study it is more important to build-up

strength through regular mobilising and gentle exercise that was helpful for both physical recovery and mental wellbeing. Achievements of targets set by individuals helped to increase motivation and continue building the exercise routine.

## 5.8 Brain fitness

It is not uncommon to view brain fitness as important in any situation. In any challenging situation it helps to be mentally sharp, to process information quickly, find strategies to solve problems, learn new information and make wise decisions. Brain fitness can also help to regulate emotions. These mental and emotional abilities can therefore help us to tackle problems and challenges and recover from setbacks (Southwick and Charney, 2012). A number of studies have investigated the impact of stress on mental functioning and the brain concluding that harmful conditions such as chronic stress, neglect and abuse can harmfully produce changes (Bremmer, 2002; Scaer, 2005). Like physical fitness where physical fitness can produce training specific muscular changes in the body, we can similarly enhance brain fitness through a series of brain exercises to improve cognitive abilities.

The value of brain fitness in the transplant process is within the learning required pre-transplant to enable preparation and through the learning and repetition to get through challenges in recovery, steps to discharge and learning a new medical regimen. As mentioned in the previous section, some participants found the recovery process frustrating and sometimes both physically and emotionally demanding. However others demonstrated various coping strategies that enhanced brain fitness and learning, helping to enhance cognitive abilities, situational awareness and emotional regulation.

Initial communication during the pre-transplant phase was key for preparing participants understanding of their diagnoses and what was to follow. Participant 1, was keen to take control and responsibility over her treatment plan, fighting for a better prognosis and seeking the best treatment possible. In her unique situation, her initial prognosis and care

plan was for end of life care but she refused to accept this, eventually having her care managed by two teams in different parts of the country. She took responsibility to ensure adequate communication between the two teams was efficient.

Um, Yeah and I felt a lot of it, my husband and I, both of us, felt that we had to be totally in control because information wasn't going from B to L or L to B, I had to bring my own...

Participant 1

In this case, participant 1 had to be able to interpret the important information to communicate effectively between each medical team, using her own mental capacity to decipher and process the medical information and communicate between the two medical teams in charge of her care. In some respects many individuals with chronic illnesses require the ability to manoeuvre themselves within the complexities of the NHS system. A lack of 'brain fitness' or ability to do this can cause difficulties in accessing treatment and health care required. Learning about the healthcare system in itself is a challenge and part of building brain fitness when managing a chronic illness.

I've probably learnt a lot about the healthcare system, um [pause] I think I've learnt, yes, in terms of the healthcare system, I've learnt how good the people are that are the specialists, um, and they really are to be admired. Um [pause] I've, I've learnt what a challenge it is to recover from a big operation.

Participant 20

Following the transplant operation there is some initial impact from the anaesthesia that prevents rational thinking for participants. Several participants were affected with the hallucinatory effects of the anaesthesia.

I felt I was fine. I said to the doctor when I woke up, 'I need to go for a run now on HH'

Participant 1

My husband tells me that, um, when I was under the anaesthetic, like, every now and then I'd, sort of, you know, wake up a little and I'd start pulling my, you know, all my things off and start, um, kicking and biting even. He was saying to me that I would actually, like, bite, and the doctors must have said to him that it's, that it's the drugs, like, the very strong drugs. But, um, still to this day I don't believe him because it's not my nature to be like that sort of person!

Participant 28

However, once the anaesthetic period was over, most participants found ways of coping that engaged their brain or enabled routine brain functioning for daily living. Participant 22 was always keen to return to work after a stressful physical period. The routine and familiarity of work helped her to engage her brain, challenge herself and feel normal.

That is kind of my way of dealing with lots of, when I get under pressure. Um, so I'd often be in hospital for a week sick and quite, you know, I was really quite ill with raging temperatures and horrendous pain and vomiting and all sorts of problems, and then go back to, as soon as I literally walked out of the hospital I'd go back to work. Yeah, because I, that was my way of coping and I didn't really know any other way of dealing with it. And I, kind of, figured staying at home wasn't going to solve the problem either...

Participant 22

Other participants talked about their use of quiet reflection, meditation or mindfulness. Mind fitness entails having a mind which is efficient for mental agility, emotional regulation, attention and situational awareness (of self, others and the wider environment (Stanley and Jha, 2009). Many recent studies and books describe training programmes for enhancing mind fitness (Begley, 2007; Kawashima, 2008; Levy, 2006). Mindfulness-based stress reduction (MBSR) is an adapted form which has been successfully used within medical and mental health settings, corporations, prisons and elementary schools (Stanley and Jha,

2009). With mindfulness as its core component, it is a process of “bringing one’s attention to the present experience on a moment-by-moment basis” (Marlett & Kristellar, 1999). As mentioned previously, participants’ use of mindfulness not only crosses over with aspects of faith and pain management but also in brain fitness.

[in describing his use of mindfulness meditation] Calming me is its, er, it, it [pause] I, I think it was pretty much that, the one central thing that I could hold on to, because I couldn’t move, you know. I couldn’t [pause] I was in control suddenly, do you see? And, er, it was the only way I could reach that state of control, if you like. I mean, it sounds strange but by letting go of things, you know?

Participant 16

And I also analysed the pain a lot, sat, coz there was nothing else to do really, so you sit all night in the dark on the sofa going 'is there a way of enjoying this? or is there a way of...?' and I think, I heard an Olympic athlete being interviewed and they said that the way they address pain is in exactly that way. That they see it as an achievement to overcome the pain threshold and I thought 'Oh! I could do the right thing!' That was post-transplant actually, erm, I just heard an interview with one of the athletes and I thought 'Oh! That's what I was doing!' You know, just analysing it. Concentrating on it, deal with it.

Participant 19

There is growing evidence that increasingly supports the efficacy of mindfulness-based interventions. Clinical studies demonstrating the improvement in many physical and psychological conditions, decreasing mood disturbance and stress and positively altering emotional experience through reduction of negative mood states and improving positive wellbeing (Baer, 2003; Broderick, 2005; Stanley and Jha, 2009).

Other coping strategies that engaged cognitive function included the use of writing. Participants found writing provided them a route to communicating with friends and family to engage support (participant 1), writing formed as part of their art and work (participant 19, writing as a process to bond and reflect (participant 20) and writing to communicate ones struggles to the rest of the world (participant 23).

So I set up erm, well my husband did it coz I can't really use computers very well but I had um, on the internet I could do an email press one button and it would go to everybody, all the family and all the friends, so everybody knew everything I did, almost each day. I would just write a little bit so that everybody knew. "feeling a bit shit today" or you know...and it was quite cathartic for me to do it. To be able to write down what I was feeling. And in fact it was something again I was going to do afterwards which was suggested by so many people. It needs to be a book.

Participant 1

[Participant 19 was a musician and artist who kept diaries as part of his work] All the time, I mean if you read the diaries...I kind of convert all that kind of thing into a story um that the life in the ward, the stories that people would say, you know the bus conductor who was dying I think, who'd talk about his bus route and then would suddenly remember 'you know, me and my wife, we haven't been out dancing since the early 60's' things like that, you know ordinary life which was there in the transplant ward. It was quite amazing I think. I mean I did drawings of people that kind of thing, [showing bits of diary]

Participant 19

...another thing that I'm writing at the moment is something about us, um, which is called, 'The Year We Grew Up Together', um, because that's what it feels like. We've

both been battling against something, um, but shared a lot of experiences during that time, um...

Participant 20

Yeah, basically around my own experiences and it's going to be called, The Good, The Bad, The Ugly and The Dead. And I've started at the ugly phase which is with the seizure, the day of the seizure.

Participant 23

Brain fitness, similar to physical fitness requires discipline to continue to enhance and improve. This can be a challenge. However, similar to physical fitness, integration cognitive and brain exercises can be integrated into daily routine through setting goals and recognising achievements.

## 5.9 Cognitive and Emotional Flexibility

Southwick and Charney (2012) refer to cognitive and emotional flexibility as an ability to be flexible in the way one thinks and reacts emotionally to challenges and stress. An ability to be flexible in approaches to coping, even using a wide range of coping styles. Key types of coping that they refer to were: acceptance; cognitive reappraisal; learning and humour. All of these were demonstrated within the interview with participants interviewed. Some participants were particularly good at flexibly using a range of these coping strategies. Generally it was found that amongst all participant strategies such as acceptance and cognitive reappraisal were used to some extent.

Southwick and Charney (2012) discuss that acceptance is the ability to effectively engage in problem oriented and goal-directed coping whilst keeping vigilant and acknowledging rather than ignoring potential road blocks. Although avoidance and denial are seen as generally counterproductive mechanisms that are short term solutions to problems, they may stand in the way of growth and learning. Participant 14 describes how



counterproductive his denial was of his alcoholism and the lack of health care seeking that led him to have liver failure:

It's, its, yeah. And I think, I think it's partly [pause] partly the, the problem of someone who has got a, er, an addiction problem, you know, it, it's the denial that comes in. You're not just denying it to everybody else, you're trying to deny it to yourself for a long time....That's right, yes. It was, it was sort of thinking, you know, oh, oh, you know, this thing [unclear] sort of the male bravado, you know, I'm a man, I don't need anyone's help, I can sort this myself, sort of thing and it's, it's not too... it's too late, you know, oh god, no, I can't do it, I need someone else to [overtalking].

Participant 14

Throughout the findings acceptance has been discussed as part of realistic optimism and facing fears. Acceptance requires one to not only acknowledge the reality of the situation but also assess what can be changed and redirecting efforts to what can be done. Thus the concept is similar to realistic optimism but also just sitting with the facts and the reality that is in front of an individual. Much of acceptance was demonstrated as acceptance of the reality of death, understanding that 'what will be, will be'. These excerpts will not be repeated here, but can be referred back to in *facing fears*. Participant 13, acknowledges that acceptance is a way of coping that he uses.

I'm just one of these type of people who accept what's happened and get on with it and I'm grateful for that... very grateful

Participant 13

Acceptance is key to tolerating highly stressful situations in those who have survived extreme environmental hardship and among highly disabled learning-disabled adults (Siebert, 1996; Gerber and Ginsberg, 1990).

Cognitive reappraisal is the ability to cognitively reframe adverse or negative events in a more positive light (Southwick and Charney, 2012a). It is strongly associated with resilience,

moderating the relation between severity of life stress and depression (Troy and Mauss, 2011). Resilient individuals often find that through cognitive reappraisal, trauma has provided them opportunities for learning and growth as a person (Park et al, 1996). Benefits that can develop include greater compassion for and acceptance of others; building closer bonds with family and friends; a greater sense of community and kinship with humanity; renewed faith; appreciation of life and a new sense of meaning and purpose (Tedeschi, Tedeschi, Park, & Calhoun, 1998; Anderson and Anderson, 2003).

Despite the experience of deteriorating health and life threatening surgery, some participants still discussed being grateful for their experience, believing that the experience provided a second chance at life to learn from previous mistakes and to re-prioritise what is important, thus reframing the difficulties that they experienced into a learning process.

I had too much to do. And, er, you know, now I, I really wonder quite how I got like that! So, you know, it's... in many ways I, I'm grateful for my, my liver and for the experience, you know.

Participant 16

P:...its been a long journey and it seems to be a kinda logical conclusion in a way, it's clarified my thinking in a way about everything! It's great!

P: Coz I've actually said, I highly recommend it [laughs]

I: Well like you say, how life changing and it's like facing death

P: Nearly dying is great! I mean really! Because er, yeah, for all the obvious reasons

Participant 19

Reappraisal through using humour was also particularly important to some participants. Participant 22 discussed that she tried to keep a sense of humour throughout, even after feeling emotional. Thus she was not avoiding her emotions but trying to see the funny side to certain situations.

I know, it was really gross, but it was kind of funny at the same time! I was like... and I then I'd sit up and it... and everything would come out and I'd go, oh, guys, failure! Yeah, I mean I tried to keep a sense of humour throughout, which I think I tended to do most of the time, ah, even after a few tears you, kind of, yeah.

Participant 22

Participant 19 used humour to describe his experiences of falling ill, treatment and the transplant process throughout. In his description below, Participant 19 story-tells his experience of going to an outpatient appointment following his first call for a transplant which turned out to be not useful. He uses story-telling and humour to engage the funny side and process his emotions around this 'failed' opportunity.

Unfortunately that Monday night's liver wasn't useful, and I had an appointment at the UCH, which is hilarious really coz looking at my diary in retrospect, because I'd been up all night here went straight to UCH and there was a harp player in the foyer and an old lady said 'they don't normally have music play here do they?' to me. I said, 'I don't know, I'm not sure about the instrument' she said 'what dear?' 'It's what they play in heaven isn't it?' she said 'where dear?'... I believe my name was called! [laughs]

Participant 19

The effectiveness of humour used as a coping mechanism has been recorded for cancer patients (Carver 1993), surgical patients (Culver, Arena Antoni, & Carver, 2002) and combat veterans (Hendin & Haas, 1984). Martin (2003) has found that when humour is used to reduce the dangers of stressful situations, it can be associated with resilience and ones capacity to tolerate stress.

## **5.10 Making meaning, purpose and growth**

The tenth and final protective factor brings a variety of components discussed in both sections 1 and 2 together. Many areas of psychology have investigated and shown interest in

the area of meaning (positive psychology, Steger 2009; cultural psychology, Mendoza-Denton & Hansen 2007; emotions, King, Hicks, Krull & Del Gaiso 2006; health psychology, White, 2004; and Clinical psychology, Hayes, Laurenceau, Feldman, Strauss & Cardaciotto 2007). Baumeister (1991) proposed a definition of meaning as “mental representation of possible relationships among things, events and relationships. Thus meaning connects things”. Therefore making meaning, purpose and growth highlights components of areas already discussed that brings meaning through the connection of the participants’ journey, protective factors to the individuals interviewed within this study.

Southwick and Charney (2012) discuss meaning, purpose and growth through the idea that meaning can give strength and courage, and through having a clear and valued purpose which can strengthen resilience. In this study, where health deterioration and transplantation is the primary stressor, this is less relevant. Therefore making meaning, purpose and growth will focus on two areas: Meaning through storytelling and Posttraumatic growth.

### **5.11 Meaning making through storytelling**

The nature of collecting data through semi-structured interviews is relatively neglected in discussions of qualitative research. Mills (2001) points out that the interview process, the social practices and its processes can be a learning point in itself. Thus, consideration must be paid to the many aspects of the interview context and variables such as the location, relationships and the assumptions brought into the process and recognise that the nature of the interview itself is a type of social interaction. Kvale (1996) discusses the interview as “a conversation that has a structure and a purpose” and thus the exploration of the patients’ storytelling of their journey (section 1) creates the framework for purposeful conversation about having a liver transplant. Additionally, where the necessity of narrative structure in writing about traumatic experiences has been explored (Smyth, True & Souto, 2001) and suggests that narrative formation in writing may be required to produce a variety of health

benefits; it could also be implied that the structure and purposeful conversations within the context of semi-structured interviews could similarly help develop narrative formation for the benefit of health. In writing, the explanation of the effects have been explored and is believed that the act of converting emotions and images into words changes the way a person organises and thinks about the traumatic or stressful event. Once in narrative formation the stressful event can be summarised and assimilated more easily and reduce distress (Greenberg, 1995). Several researchers have also explored the belief that if an individual is upset about a traumatic event, memories are not integrated into a personal narrative and can result in the memory being stored as sensory perceptions, obsessional ruminations or behavioural re-enactments (Van der Kolk & Van der Hart, 1995). Participant 13 describes similar sorts of fragmented memory, however insists that meaning from his experience does not come from these memory flashbacks but from the donated liver. Despite his view that these memory flashbacks are not part of his 'answer', he regularly discusses his flashbacks and the contexts within which they occur throughout the interview, possibly indicating their importance to him after all.

It doesn't come up in conversation much, it's when the mother of my children, she says 'are you still trying to remember things?' I'm going 'no, I'm not trying to remember anything, but every now and again I get little flashbacks, right? But I'm not, I'm not looking for answers.....Whereas I'm not looking for answers. My answer is there. It's all...it's my stomach, my answer, yeah? And here I am, speaking to you, so I've been dealt with. A...these little things of memory coming back just absolutely for no reason at all

Participant 13

As previously mentioned, several participants use writing as a way of exploring their experiences and emotions on paper (see also *Brain Fitness*). Writing about traumatic events has been found to produce a variety of health benefits which include physical health

improvement, psychological wellbeing and physiological functioning (Pennebaker, 1993 & Smyth, 1998). Through the narrative structuring process of writing, integrated thoughts and feelings can more constructively access meaning, as participant 19 demonstrates through his use of diary writing.

I: So something, something has definitely changed in the way that, in the way that you look at fear, that you look at pain, that you look at your anxiety and reflect on it. You've clearly taken years of writing through using your diaries and reflecting upon what certain things mean to you.

P: Yeah, this is the weirdest one, and it just feels like, if you kind of face death, you only live twice. Once when you're born, once when you face death. Um, which is what the Japanese guy says to James Bond! [laughs] and er...it's true, because you really start living. If you face death and survive.

Participant 19

Overall however, meaning making through storytelling (particularly for people trying to make sense of difficult or traumatic experiences) enables narratives which help individuals to make sense of their experiences (Weber, Harvey & Stanley, 1987). Thus, exploration of the experience of having a liver transplant as discussed in section 1 is still a vital part of making meaning for the participants and development of resilience.

## 5.12 Posttraumatic growth

Tedeschi and Calhoun (2004) define posttraumatic growth as "The experience of positive change that occurs as a result of the struggle with highly challenging life crises". It can occur alongside attempts to adapt to highly negative acts of circumstances that can engender high levels of psychological distress. Traditionally, psychology, medicine and related disciplines have tended to focus on ways in which traumatic and stressful events have led to psychologically and physically distressing problems. However, the growing literature in

posttraumatic growth has reported growth experiences in the aftermath of traumatic events. The assumption that trauma can often result in disorder however should to not be replaced with the expectation that growth is inevitable. Instead Tedeschi and Calhoun (2004) find that in personal distress, growth and learning often coexist.

Tedeschi and Calhoun (1996) highlight 3 domains to assess posttraumatic growth (within their Posttraumatic Growth Inventory (PTGI): Changes in the perception of self; changes in the experience of relationships with others; changes in ones philosophy of life. Below are some examples of excerpts from participants demonstrating different types of posttraumatic growth.

Type	of	Examples
Posttraumatic		
Growth		
Changed	Perception	<p>"And do you know the funny thing is, I never get scared now...I had to do a reading at somebody's wedding recently, I didn't have to, they asked me and HATE standing up and doing things in front of other people! Oh! And my stomach would turn and I'd get Urgh!!... I said, "Yeah, alright!" and everybody was going "Oh God, you must be really nervous!" and you know I keep looking to find that nervousness...it's not there." (Participant 1)</p> <p>"Before I wasn't sure, I mean I just had a vague terror and was gradually coming to the realisation that my dad and counselling and the hell I went through with the mother of my daughter and blah blah blah...its been a long journey and it seems to be a kinda logical conclusion in a way, it's clarified my thinking in a way about everything! It's great!" (Participant 19)</p> <p>"Um, it's made me much more aware of myself, both mentally and physically. Um, you know, you know, I should, should listen to my body more and it's made me aware that it's, it's not, um, what's the word? Cowardly; it's not weak to ask, to ask for help." (Participant 14)</p>
of self		



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**Changes in the experience relationships with others** "[NB: Prior to transplant he was avoiding family] I, I quite agree. Yes, I think he, he's put that well, yeah. Um, I spend a lot of time with my family and, er, yes, that is... I just don't, er, seem to find things that, that make me anxious or, you know, so, [pause] you know, life's good. Life's good." (Participant 16)

"[Talking about how his relationship with his parents have changed] Yes, I think it's changed for the better, because, you know, they've seen, they've seen me admit the problem, to have something done about it, deal with it, cope with it and now having a... something in place to, to stop it happening again. And I think it's actually brought us closer." (Participant 14)

"my son, in contrast, we've talked an awful lot. Um, in fact, I'm... another thing that I'm writing at the moment is something about us, um, which is called, The Year We Grew Up Together, um, because that's what it feels like. We've both been battling against something, um, but shared a lot of experiences during that time, um..." (Participant 20)

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**Changes in ones** "And to, and to try and make something worthwhile, you know. Make, make my life not just be, oh, feeding someone else's benefit

**Philosophy of life** and profit but actually, you know, make my life meaningful. Do something worthwhile." (Participant 14)

"Well, um, [pause] I'm not sure if I've learned it myself or whether it's been imposed on me, but it's, it's to avoid stress. Very simply. And, ah, it can kill you that stuff, you know, so I, I think that's... is... the... one of the things that, that's got into my system now, you know, I just seem to be able to avoid it very easily I'm glad to say."

"I had too much to do. And, er, you know, now I, I really wonder quite how I got like that! So, you know, it's... in many ways I, I'm grateful for my, my liver and for the experience, you know." (Participant 16)

"Um, and that was a really stark realisation of, of how serious... of, of just how serious the situation was, and, um, things like getting this better, so much more important than, you know, running yourself into the ground through, um, a load of stress. You know, I mean we... yes, we need money to live, and you, you find a way. It doesn't have to be... sorry, you find a way, and it's legal. Um, but you, you don't have to run yourself into the ground."

"Yes, and [pause] and it, it has changed my priorities. Um, coming on a rush hour train this morning, um [pause] was really funny. I was just observing the people on the train and thinking, why are you doing this? Um, and people with suits and, and in running shoes on, which they're clearly going to change when they get into their office, um [pause] but I was thinking, why are you running away from home? Um, it seems, it, it seems wrong to be running away from the people that you love, um, to go to a place to earn

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money. But money's only a form of exchange. Um, it's, it's a means to an end, not an end in itself, I think. Um [pause] yes, so it has [pause] made me view life differently." (Participant 20)

"Yeah, yeah. I do think, though, um... I suppose I have learnt that, you know, your life can be taken away from you just like that, and you need to live it. And, you know, and, and this is how I feel with, with O, you know, you need to live your life. Don't live on, what if. Um, and, you know, I feel like I did live my life before, but even more so now, actually. It's, like, don't get het up over the things that you don't need to. It's very easy to get back wrapped up in, in your life as it was, um, but then I am an optimistic person anyway, so, um... but just don't take your life for granted, um, is, is the best philosophy." (Participant 24)

"No, I... my... instead of the, the days being full of doing nothing, which is what they were before, um, now my time is, is getting filled up. Um, and my wife and I have been away several times now, which we couldn't do before; we've been away in, in this country and we've just started to travel overseas as well and, er, so on, and we've always enjoyed travelling but now we've enjoyed travelling purely for pleasure instead of, er, business and pleasure. So, er, it's, er... there's a slightly different emphasis in terms of that; a lot more relaxing and so on. And I'm never going back to the high pressure, er, business travel that I used to do. (Participant 25)

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*5.12.1 Table: Types of Post-traumatic growth*

Pietrzak et al (2010) studies posttraumatic growth in Iraq and Afghanistan veterans and found that one of the most common areas of growth were 'changing priorities about what is most important in life'. This is similar to the current liver transplant study, where several participants talked about a change in priorities in life and focusing on less stress and more on relaxing, loved ones and activities that are more worthwhile.

Although Posttraumatic growth has similarities to resilience, and is connected in terms of building resilience, a distinction should be made. Posttraumatic growth has more of a quality of transformation, or a qualitative change in functioning (Tedeschi & Calhoun, 2004).

'Protective factors' as a concept have become firmly established in the field of psychiatric risk research (Garmezy, 1985; Masten & Garmezy, 1985; Rutter, 1979; Rutter, 1985). Its roots are within the notion of resilience, a term used to describe positivity within individual differences in people's response to adversity. Through introducing the notion of protective factors and its demonstrating that these variables are highly robust predictors of resilience, we can highlight their key role in the processes involved in people's response to risk circumstances (Rutter, 1987). However this knowledge is of little value as a means of finding new approaches to prevention. The next section will focus more on the core concept of resilience.

## CHAPTER 6: RESILIENCE AND GROWTH THROUGH DISRUPTION

### 6.0 RESILIENCE AND GROWTH

Historically, resilience is a term used to describe the elastic quality in plants. Within the dictionary it is defined as 'the act of rebounding/springing back'. This has some similar qualities to the liver itself which has a high regenerative capacity and complex functions (Michalopoulos & DeFrances, 1997; Taub, 2004; Michalopoulos & Khan, 2005c; Fausto et al., 2006).

Within humans, the concept of resilience helps us understand why one individual reacts with problems or symptoms to a minor event when another may not experience distress at all. When facing adversity resilience may provoke the promise of something good resulting from misfortune, 'hope embedded in adversity' (Dyer and Minton McGuinness, 1996). It is an 'intriguing area of inquiry that explores the personal and interpersonal gifts and strengths that can be accessed to adapt and grow through adversity' (Richardson, 2002). However 'resilience cannot be seen as a fixed attribute of an individual' (Rutter, 1987). An individual may be able to cope well in one circumstance but if the situation is different, resilience might also change. For instance, within the current study, liver transplant candidates continue to have changing circumstances throughout their time on the waiting list, during and post-transplant. There are issues with health deterioration, physical changes or complications throughout due to medication or the surgery and once discharged home within their environmental changes.

Richardson (2002) describes three waves of resiliency research that has developed over the many years of inquiry into resilience. This is similar to how this study has come to develop the core concept of resilience. The rest of this section will discuss the literature on resilience up to date and use this as a background understanding to develop a model of how resilience develops as a core concept within the current study and the processes leading to an

individuals' adaptation. The section will further discuss future implications and further investigations required to develop the care for liver transplant patients.

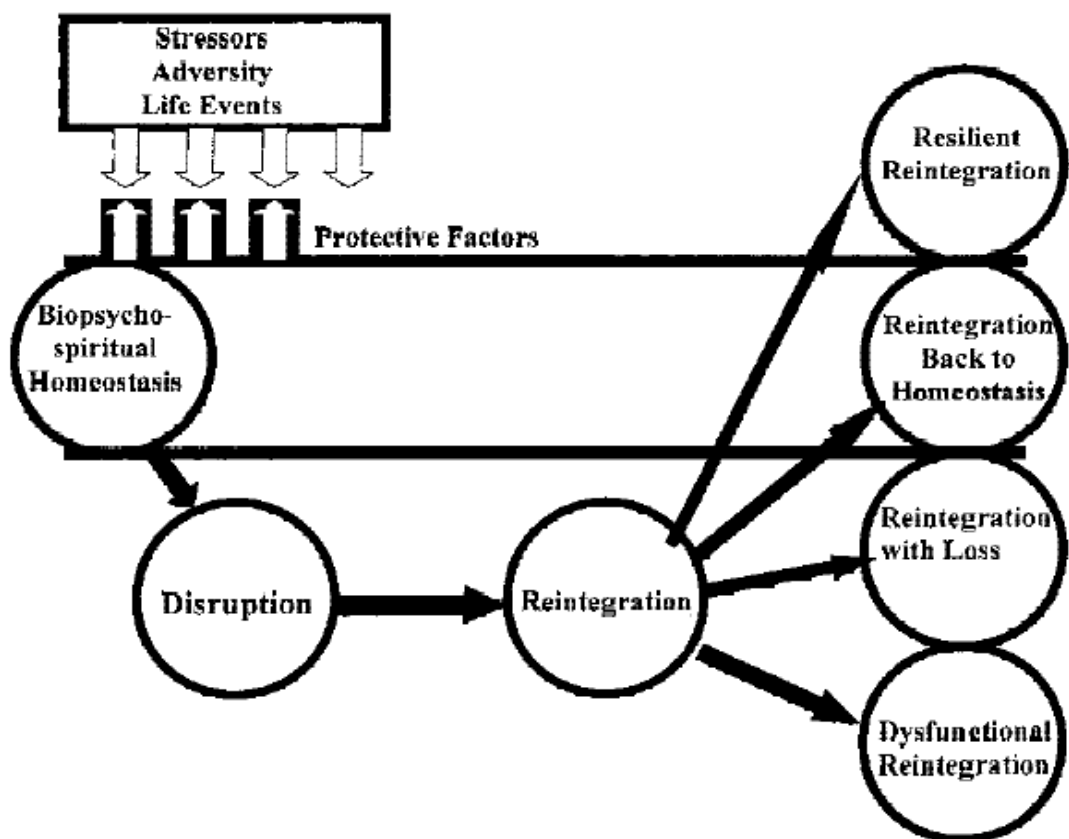
	Description	Outcome
First Wave: Resilient Qualities	Phenomenological descriptions of resilient qualities of individuals and support systems that predict social and personal success.	List of qualities, assets, or protective factors that help people grow through adversity (i.e., self-esteem, self-efficacy, support systems, etc.)
Second Wave: The Resiliency Process	Resiliency is the process of coping with stressors, adversity, change, or opportunity in a manner that results in the identification, fortification, and enrichment of protective factors.	Describes the disruptive and reintegrative process of acquiring the desired resilient qualities described in the first wave; A model that helps clients and students to chose between resilient reintegration, reintegration back to the comfort zone, or reintegration with loss.
Third Wave: Innate Resilience	Postmodern multidisciplinary identification of motivational forces within individuals and groups and the creation of experiences that foster the activation and utilization of the forces.	Helps clients and students to discover and apply the force that drives a person toward self-actualization and to resiliently reintegrate from disruptions.

### 6.0.1 Table: Three Waves of Resiliency Inquiry (Richardson, 2002)

The first wave of inquiry highlighted a paradigm shift from research looking at the risk factors leading to psychosocial problems to the identification of strengths of an individual (Benson, 1997). The situational premise of resilience was that people possess strengths or assets to help them to survive. It therefore questioned "what characteristics mark individuals who thrive in the face of risk factors as opposed to those who succumb to destructive behaviours?" (Richardson, 2002). Thus most of the first wave inquiry into resilience investigated the very factors, internal and external resilient qualities that helped people cope and 'bounce back' from high-risk, adverse situations and setbacks i.e 'protective coping factors'. The invaluable research into the list of traits, states and characteristics is exhaustive and has led to interventions targeted at teaching resilient qualities e.g. Self-esteem or self-efficacy educational packages without the underlying processes of how individuals can actually

improve these resilient qualities. These protective coping factors have been discussed with application to the current study on participants who have experienced a liver transplant.

The second wave of resiliency inquiry asked the question 'how are the resilient qualities acquired?' (Richardson, 2002). This enabled resiliency to become more defined as 'a process for coping with adversity, change, or opportunity in a manner that results in the identification, fortification and enrichment of resilient qualities or protective factors' (Richardson, 2002). Through this line of inquiry it was suggested by Flach (1988, 1997) that resilient qualities are attained through disruption and reintegration and the idea developed further through Richardson's (2002) depiction of resiliency in a model as part of the third wave of resiliency.



**6.0.2 Figure 1: Resiliency Model (Richardson, 2002)**

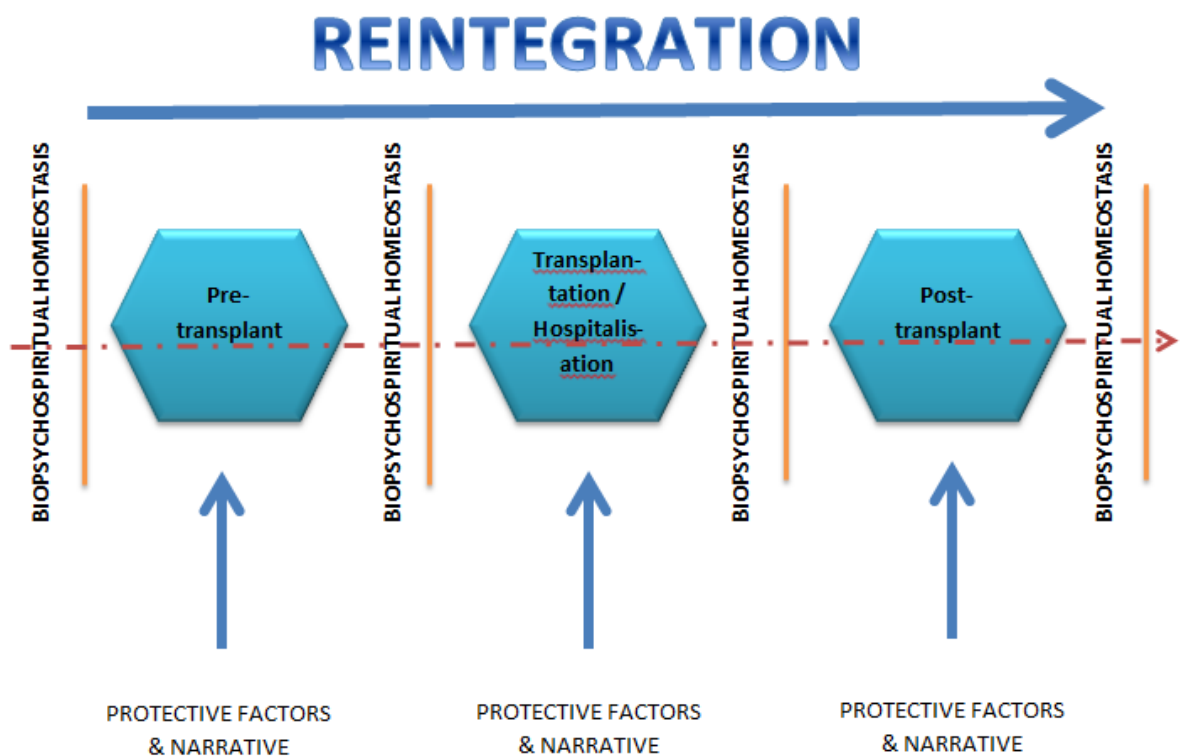
The resiliency model depicted above, highlights how individuals, through planned disruptions or in reacting to life events, have opportunities to either choose consciously or

unconsciously the outcomes of disruptions that may happen in life. Thus in the model, resilient reintegration refers to the coping processes that result in growth, understanding and increased strength or increased resilient qualities i.e. Allows a person to *adapt* to better suit their environment. Richardson (2002) explains that in the model description of resiliency, resilience begins with any point in time when a person has adapted to their circumstances in life. He uses the term 'biopsychospiritual homeostasis' to describe any point in time when an individual has adapted physically, mentally and spiritually to a set of circumstances (good or bad). He states that chronic stressors affect individuals when they are not or do not develop resilient qualities. Or have not grown through the difficulties and disruptions that have occurred throughout life. Richardson suggests that almost all (if not all) disruptions in life provide opportunities for growth and that a person can reintegrate and adapt (consciously or unconsciously) resiliently, with an attempt to return to 'biopsychospiritual homeostasis', or 'dysfunctionally reintegrate with loss'. The final and third wave of resilience inquiry therefore developed the concept of resilience further; making it clear that in a process of reintegrating from disruptions in life an individual requires a driving force to enable them to pursue wisdom, self-actualisation and altruism and for one to be in harmony with their spiritual source of strength.

Referring back to the current study under investigation, various factors must be involved in a complex and changing model for an individual who has experienced a liver transplant. Key factors required within the model include protective factors (e.g. Cognitive and emotional flexibility, realistic optimism, brain training, moral compass and altruism, making meaning, purpose and growth etc. as discussed in section 2); reintegration and adaptation back to biopsychospiritual homeostasis and recurrent and changing circumstances or multiple 'disruptions' created during each phase of transplantation (i.e. pre-transplant, transplantation and post-transplant as discussed in section 1). For those participants that were interviewed for this study, the interview process itself appeared to play a key part in re-



organising and formulating some understanding of the challenges that were faced throughout the transplant journey. One could assume that in a wider 'real life' context other liver transplant recipients might find similar ways of expressing their thoughts to organise their experiences and make meaning. Not necessarily within an interview setting but maybe through explaining their journey to friends and family or through writing diaries. In this context the interview narrative was seen as an integral part of reintegration and adaptation, willingness to talk about their experiences might even highlight characteristics of individuals willing to share their story and use of this type of coping strategy. Below is a visual representation of participants' journey through reintegration and adaptation back to biopsychospiritual homeostasis.



**6.0.3 Figure 2: Process of adaptation following a liver transplant**

At each phase of disruption individual participants might turn to different resources and coping strategies to enhance their resiliency and/or environmental circumstances may

influence resiliency in any one individual. Individuals then adjust accordingly to reintegrate resiliently or dysfunctionally.

## **6.1 Limitations, Clinical Implications and Further Research**

First phase resiliency inquiry has investigated a wide range of individuals throughout the lifespan. Intervention implementation has only come in recent years with a focus on developmental psychopathology i.e. between children and their environments (Beardslee, 1989; Beardslee & Podorefsky, 1988; Beardslee et al, 1999; Cicchetti, Rogosch, & Toth, 2000; Cicchetti, Toth & Rogosch, 1999)

Several research studies have indicated that protective factors of resilience can reduce psychiatric symptoms among adults too (Campbell-Sills, Cohan & Stein, 2006). It has also been found to enhance health-related quality of life and coping among medical populations (Viggers & Caltabiano, 2012; Wu, Sheen, Shu, Chang & Hsiao, 2013). Therefore with a chronic and progressive illness such as End Stage Liver disease and given the uncertainties and challenges that are frequently faced over a lengthy period in those who are suffering from End stage Liver Disease; interventions to support and improve resiliency may be particularly useful. Indeed with organ transplant centres relying on extensive pre-transplant candidate selection procedures (including psychological and medical assessments) intended on minimising patient risk and maximise positive outcomes (Fernandez, Fehon, Treloar, Ng, & Sledge. 2015). Robust predictors of post-transplant morbidity and mortality include psychosocial functioning, coping and social support (Corruble et al. 2011; Stilley et al. 2010). Therefore an increased attention to patient ability to cope and regulate psychological coping and experiences may help predict and potentially improve physical and mental health prior to and post transplantation. Fernandez et al (2015) suggest that resilience could indirectly promote health by helping patients manage liver disease better through diet and areas of treatment management.

An article on adolescent cancer adjustment highlights that there is a tendency to underemphasise positive health and over emphasise pathology type models when investigating psychosocial adjustment in adolescent cancer (Haase, 2004). Hasse (2004) suggests that focusing on positive health concepts such as resilience have the potential to be excellent guides for developing effective psychosocial interventions. Factors influencing positive health, such as hope, positive coping, and perceived social support, are areas that can be targeted and improved through well-developed interventions. Furthermore, 'The Committee on Future Directions for Behavioural Health and Social Science Research at the National Institutes of Health have argued for increased support for the study of "positive health"' (i.e. protective variables such as resilience, positive coping, meaning and purpose, and social and emotional support (Singer & Ryff, 2001). In the additional context of cancer and other chronic illnesses, Haase, Heiney, Ruccione and Stutzer, (1999) define development of positive health, as the process of identifying or developing resources and strengths to flexibly manage stressors to gain a positive outcome and a sense of confidence, mastery, and self-esteem.

Resilience and resiliency is clearly still a developing concept in current research. This creates opportunity for initiating thoughts into further developments of the current study in terms of working towards implementation of an intervention to minimise risk and maximise positive outcomes for Liver transplant. This study recognises limitations, in particular the small sample and data collection within a single site only. To further validate findings, wider investigation within a larger cohort across several sites may be useful. With both qualitative designs to further investigate the phenomenon of resilience in patients who have experienced a liver transplant and/or quantitative studies analysing the core protective factors that may be involved or a factor analysis have potential pathways for future research. Systematic reviews to investigate potent vulnerability and protective processes affecting Liver transplant candidates can then act as an anchor for designing of interventions.

An additional limitation is the understanding that this study appeared to attract a self-selecting cohort. It is possible that for those patients whose liver transplant surgery did not go so well, they continued their time under critical care within hospital or felt too unwell to engage in such research. Alternative methods of recruiting could have used recruitment on the ward following surgery or researchers recruiting by sitting in follow up clinics. At the time the study was carried out, these methods were considered too intrusive for patients. A self-selecting cohort may not necessarily be representative of all patients who have received a liver transplant however for highlighting resiliency and with further intention of improving wellbeing for those who have experienced liver transplantation, 'well adapted' participants can be particularly useful to learn from.

### **6.3 Conclusion**

What started as a small level Grounded Theory study has highlighted a key area of research and area of interest that is particularly popular within current psychology at the moment. Participants within the study provided an overwhelming amount of evidence for protective factors rooted in the core concept of resilience. Further investigation into the core concept of resilience has since uprooted an immense amount of research which in turn supported the development of a specifically designed model for experiencing a liver transplant. The concept of resilience and its associated evidence suggest several implications for prevention. Emphasised in the current study and in resiliency research is the idea that future interventions may need to take a different approach and turn away from traditional approaches of focusing on risk reduction. Instead, development of resources to enhance protective coping and early input may impact future resiliency. Usual practice tends to list deficits that predispose, enable, and reinforce negative behaviours, similar to psychological assessments carried out during the pre-transplant phase (Fergus & Zimmerman, 2005). However a resilience approach has wider emphasis on assets and resources as the focus for

positive adaptation due to the multidimensional nature of the potential for resilience interventions to cut across and enhance protective factors (Fergus & Zimmerman, 2005). Indeed, well established therapeutic models are now seeing the advantages of a resilience based approach. For example, Padesky and Mooney's (2012) 'Strengths-Based Cognitive-Behavioural Therapy', suggests a 'shift in therapy perspective from ameliorating distress to focusing on the patients' current strengths. Future ways of supporting chronic illness interventions with the potential of multiple traumas may benefit from similar types of strength based interventions.

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# **SECTION B: APPENDICES**

# **APPENDICES: SECTION B RESEARCH**

## Appendix 1: Recruitment Documentation



Dear

I would like to invite you to participate in a research study looking at 'the process of adaptation to daily living after receiving a liver transplant'. This study is being carried out by Davina Wong, the Trainee Health Psychologist/Assistant Clinical Psychologist working with the Renal and Liver Clinical Health Psychology Service. The study is part of a Doctorate qualification in Health Psychology with City University London.

You will find an information leaflet about the study with contact details should you decide to participate. I would be very grateful if you could take the time to read this information and contact the research team if you would like to participate or if you want any further information. **If you would like to hear more about this study and/or would like to take part please get in touch with us by phone, email or post as listed below:**

1. Phone:
  - a. [REDACTED] (leave a message for Davina Wong, researcher, with your name and contact number on the answer phone if no one is available to take your call),
  - b. [REDACTED] (Linda Selves, Senior Liver Transplant Coordinator)
2. Email: [REDACTED]
3. Post: You can send back the enclosed Initial Contact Consent Form in the FREEPOST envelope provided.

If we do not hear from you after 14 days you may receive a follow up phone call from the research team to ensure that you received the information about the study and have had enough time to decide if you would like to take part.

Many thanks for your time.

Consultant Hepatologist



**Initial Contact Consent Form**

**Study: The process of adaptation to daily living after receiving a liver transplant**

**I am interested in finding out more about the study**

I confirm that I have read and understand the information sheet (dated December 2012, version 4) and would like a researcher to contact me to discuss it further. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. I understand that my medical care and legal rights will not be affected in any way.

**Print name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

---

**Preferred telephone numbers:** \_\_\_\_\_

**It is OK to leave an answer phone message on this number?:** YES / NO

**When is the best time to call?:** \_\_\_\_\_

**Email address (optional):** \_\_\_\_\_

## **Participant Information Sheet: The process of adaptation to daily living after receiving a liver transplant**

We would like to ask if you would be able to take part in a study looking at the experiences of people who have had a liver transplant. Before you decide whether you would like to join in, it is important to understand why the research is being done and what it will involve for you. Please consider this leaflet carefully and feel free to talk with your family, friends and contact us for further information.

### **Background and aim of the study**

The Royal Free Hospital is interested in how we can help patients following liver transplant surgery. In this study we hope to explore the experiences of patients who are adjusting to everyday life following liver transplantation. The overall aim of the study is to gain a better understanding of the process of adaptation to daily living after receiving a liver transplant. The hospital considers it important to base its service on patient experience; this information is hard to access in any other way, except to ask patients directly about their experiences. The study is part of a Doctorate qualification in Health Psychology with City University London.

### **Why am I being asked to take part?**

We are asking a number of patients who attend the Liver Transplant Service, who have had a liver transplant within the last 3 years if they would like to take part in this study.

### **What is the procedure?**

We are hoping to carry out interviews between 1 hour to 1 ½ hours long with working aged adults. At least 8-15 people will be interviewed altogether and depending on how the emerging data from the research develops, we might ask for consent for a second interview. Interviews will be carried out by the Assistant Clinical Psychologist working with the Renal and Liver Clinical Health Psychology team, whom you will meet beforehand and be given the opportunity to ask any questions that you are worried about. You will be audio recorded.

**Will my interview be confidential?**

Anything you say in the interview will not be told to anyone else. Your name and any places or other names that you mention will be changed for the study. Confidentiality will be respected wherever possible, subject to the need to consider the safety of yourself and others.

Audio tapes and any other data will be stored securely within the hospital and destroyed after a period of 3 years according to hospital policy. As interviews will be audio-recorded, direct quotes may be used in the reporting of the research, however all quotes used will be made anonymous.

**Do I have to take part?**

No, it is entirely up to you. You have 14 days to decide whether you would like to take part. If you do, you will need to contact the research team to let them know you would like to take part (see below for contact details).

An interview date and time will then be arranged with you. Prior to starting the interview you will be given the opportunity to ask any further questions and then asked to sign a form giving your consent to take part in the study. You will be given a copy of this information sheet and your signed form to keep.

**You are free to stop taking part at any time before the interview and you can withdraw your interview data within 14 days following the date of your interview.**

If you decide to stop, this will not affect the care you receive.

**What will happen to me if I take part?**

You will only be involved for a maximum of 90 minutes altogether. This allows for a maximum 1 ½ hour interview, with breaks at a pace that you would like to take. Depending on how the emerging data from the research develops we might ask for consent for a second interview of similar length. The researcher will try to arrange a suitable time and place convenient for both parties. If you would like the interview to take place at the hospital we can try to arrange for it to coincide with an up and coming appointment. Interviews at the hospital will take place in a private room in the Royal Free Hospital or a home visit can be arranged depending on your location. The full study lasts for 6 months; however you will only need to meet with the interviewer to complete the interview. Your only responsibility is to be able to communicate to the interviewer you experiences following liver transplant surgery. Your GP will also be informed of your participation in the study and your

Consultant Hepatologist unless you state otherwise.

**What if something goes wrong?**

Should you be affected if something goes wrong while the study is taking place, the research will be covered by indemnity and insurance and you will be compensated. A list of other counselling and community options will be made available should you require further support.

**What if I have other concerns that I would like to discuss?**

If you have a concern about any aspect of this study, you are welcome to speak to the researcher Davina Wong, Trainee Health Psychologist/Assistant Clinical Psychologist on [REDACTED] or [REDACTED] (Kidney and Liver Psychology, Kidney and Urology Outpatients, Upper 3<sup>rd</sup> Floor, Royal Free Hospital) . You can also seek advice on the study by speaking to Linda Selves, Senior Liver Transplant Coordinator on [REDACTED] (Liver Transplant coordinators office, 8<sup>th</sup> Floor, Royal Free Hospital). If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained through the hospital.

**Who is funding this study?**

This study is sponsored by City University London.

**Is this study conducted in an ethically appropriate manner?**

This study has been reviewed by the Research Ethics Committee, London-Harrow and also by the City University Ethics Committee. In order for this study to be carried out, both Ethics Committees have given ethical approval for the procedures to go forward.

**Will I be able to find out the research outcome?**

If you would like to hear about the findings of the study after it is completed you can tick the box requesting for a summary of the outcome at the bottom of the consent form. A summary of the study will then be posted to you. This study will also be submitted for publication in a peer reviewed journal which is in public domain.

**Possible benefits of taking part**

We cannot promise you any direct benefit from the study but the information we get might help treat other post-liver transplant patients who are having difficulty adjusting to daily living following

their transplant surgery. We hope that this study might influence best practice in liver transplant services.

**Contact Details:**

If you would like to hear more about this study and/or would like to take part please get in touch with us by phone, email or post as listed below:

1. Phone:

a. [REDACTED] (leave a message for Davina Wong, researcher, with your name and contact number on the answer phone if no one is available to take your call),

b. [REDACTED] ( Linda Selves, Senior Liver Transplant Coordinator)

2. Email: [REDACTED]

3. Post: You can send back the enclosed Initial Contact Consent Form in the FREEPOST envelope provided.

If we do not hear from you after 14 days you may receive a follow up phone call from the research team to ensure that you received the information about the study and have had enough time to decide if you would like to take part.

Patient Identification Number:

**CONSENT FORM**

Title of Project: The process of adaptation to daily living after receiving a liver transplant.

Name of Researcher: Davina Wong

Please read the following statements initial each box and sign overleaf

1. I confirm that I have read and understand the information sheet dated **March 2013 online recruitment version 1** for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw prior to and during the interview without giving any reason and without my medical care or legal rights being affected. You will also have a 14 day period following the interview where any interview data collected prior to withdrawal can be removed from the study and destroyed.

3. I understand that once interview data has been collected I will also have a 14 day period in which to contact the researcher to have my data withdrawn from the study. I do not have to give a reason to do this and my medical care and legal rights will not be affected.

4. I understand that data collected during the study may be looked at by individuals from The Royal Free London NHS Trust and the regulatory authorities, where it is relevant to my taking part in this research.

5. I understand that my interview will be audio-recorded.

6. I understand that anonymous direct quotes may be used from my interview in the reporting and publishing of this study.

7. I agree to take part in the above study (please provide address to researcher).

8. I would like to request a summary of the research once the study has been completed.

\_\_\_\_\_

Name of Patient

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

\_\_\_\_\_

Name of Person taking consent

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

## Appendix 2: Initial Interview Schedule

### Processes of Adaptation after Liver Transplantation

#### Interview schedule notes

Participant number:
Brief medical background:
Leading up to transplant:

Transplantation and hospital stay:

Post-transplant:



Main challenges adaption post-transplant:

# **PUBLISHABLE ARTICLES**

## **Title: Supporting Patients Better on Self-Care Haemodialysis**

### **Summary:**

**Background:** Self-care haemodialysis is cost effective and reports better health-related quality of life in patients. Support for self-care is a core component of the management of long-term conditions. Methods such as education have enabled patients to be better informed of the pros and cons of self-care dialysis options. However passive education projects are limited in understanding the processes by which they can induce increased self-care practices. Implemented interventions using psychological theories such as Self-determination theory, suggests that autonomy and competence may underlie effective self-care management in other chronic illnesses.

**Aim:** Survey to gain knowledge of how to improve support provided for individuals learning self-care dialysis (SCD) and gain understanding of how individuals overcome challenges to full self-care.

**Method:** 32 questionnaires were sent out to SCD patients across dialysis units in North London and all patients known to be on home-haemodialysis.

**Results:** Questionnaire data was analysed for descriptive data. Good feedback was reported by patients on their current experiences of support on self-care. Specific challenges in learning fell into 2 main categories: issues with needling and issues with the dialysis machine.

**Recommendations:** for service development, increased support and overcoming challenges are discussed. Suggestions of using psychological theories and communication methods such as Self-determination theory and Motivational Interviewing are raised as potential methods of improving education and promoting competence in patients as they learn self-care dialysis.

**KEYWORDS:** Home haemodialysis, self-care, self-cannulation, self-care education, self-determination theory.

## Introduction

Cost of Home-based Haemodialysis (HHD) fall within the most efficient self-care modalities (£20,764) as opposed to Hospital-based haemodialysis (HD) and satellite unit-based haemodialysis costing £35,023 and £32,699 respectively (Baboolal, McEwan, Sondhi et al, 2008). A number of studies report findings of better health-related quality of life associated with self-care dialysis modalities (Manns, Johnson, Taub et al, 2003; Kutner, Zhang, Barnhart et al, 2005). Despite these potential benefits, uptake of home-based dialysis is still low (Blake 2000; Jiwakanon et al 2010; Mendelsohn et al 2001).

Research has focused on the barriers and challenges of self-care dialysis (SCD) (Hope 2013; Cafazzo, Leonard, Easty et al 2009; Ledebø 2008; McLaughlin, Manns, Mortis et al, 2003). Support for self-care is seen as a core component of the management of long term conditions (Wagner, Groves, 2002).

This paper discusses a survey carried out with patients currently on self-care haemodialysis. The aim: to gain knowledge of how we can improve support provided for individuals learning SCD and also gain some understanding of how current self-caring patients have overcome challenges to fully self-care.

### Barriers:

Several perceived barriers to SCD have been highlighted (Cafazzo, Leonard et al, 2009; McLaughlin, Manns and Mortis, 2003) including: perceived burden on the family; fear of self-cannulation; fear of catastrophic event in the absence of nursing support; lack of self-efficacy and patient concerns about isolation. Hope, 2013 further emphasised the importance of education and how we address the current lack of understanding of SCD through the use of education and decision aids. Ledebø (2008) highlighted motivation as the strongest driver for choosing to learn SCD with the complexity of the dialysis procedure and length of time on dialysis also being problematic. Ledebø explained that lack of motivation was caused by

significant deficiencies in knowledge of and attitudes regarding SCD and recommended that 'creating a thorough understanding of the pros and cons of therapy alternatives should be the foundation of building motivation'.

### **Education:**

In pursuit of developing a sound education strategy to aid patient modality choice Manns, Taub, VanderStraeten et al's (2005) education intervention included potential advantages of SCD (e.g. Flexibility in scheduling dialysis, easier planning, travel and flexibility with diet and fluid intake) with differing levels of detail. Mclaughlin, Jones, VanderStraeten et al (2008) identified the perceived advantages of SCD (including all self-care modalities) associated with increased odds of selecting SCD whilst evaluating the effect of the above described educational intervention on patient perceptions of these advantages. Their findings concluded that patients who identified freedom and lifestyle advantages were more likely to choose a form of SCD. In addition they found that the provision of additional education of dialysis modality increased the patient perception of the advantages of SCD and the odds of selecting a SCD modality.

Other interventions in chronic illnesses such as diabetes demonstrate that education can improve self-care in patients (Brown, 1999). However, the processes by which this occurs are unclear. Research on self-determination theory (SDT) (Deci & Ryan, 1985; Sheldon, Williams & Joiner, 2003) has suggested that autonomy and competence may underlie effective self-care management in diabetes (Senecal, Nouwen & White 2000; Williams, Freedman, & Deci, 1998). According to SDT individuals are "autonomously motivated when they experience volition and choice while behaving; they are controlled when they experience pressure or coercion...further, people perceive themselves to be competent when they feel able to control important outcomes" (Williams, McGregor, Zeldman, Freedman, Deci, 2004)

## Self-cannulation:

Several studies (Wong, Migram, Halifax et al, 2009; Cafazzo, Leonard, Easty et al, 2009; Pipkin, Eggers, Larive et al, 2010) highlight patient anxiety of self-cannulation. Advantages emphasise levels of patient skill to staff led-cannulation can be quickly achieved; the patient will always be present for cannulation; decrease in waiting times and frustration for the patient if nurses are busy; independence and empowering the patient (Brouwer, 2011; Richard & Engebretson, 2010). Cannulation experience and knowledge level of nurses can have significant impact on long-term survival of the AVF. Bradbury, Fissell, Albert et al (2007) argue that patients are likely to have increased familiarity and experience with their own AVF, thus reducing any impact nurse knowledge and experience may have on patient long-term survival. However, best practice and education is mainly based on opinion and clinical expertise as there is a paucity of clinical studies on self-cannulation education (Brouwer 2011; Hudson and Macdonald, 2010).

Hudson and Macdonald (2010) looked at the nurse's role in the teaching process using Orem's self-care deficit nursing theory to update and develop patient-teaching resources for self-cannulation. Orem's theory (1980a, 1980b) upholds that individuals are capable of performing and/or desire to perform self-care activities in an effort to achieve/maintain health. It outlines strategies nurses can incorporate in their plan of care depending on the assessed self-care deficit and also emphasises the importance of patient involvement in the practical aspects of teaching (Quinn-Cefaro, 1999). However, Orem's theory knowledge deficit approach neglects specific psychological components required in learning an invasive procedure. This can be a very personal and emotional experience which can impact a patients feeling of control over a successful outcome and feelings of competence in being able to carry out the task successfully (as suggested by SDT).

## Procedures of Supporting and Training Self-Care Dialysis:

Patients are required to proceed through a series of self-care steps. Basic self-care practice e.g hand hygiene may be initially taught to patients as standard practice (level 1 – preparing for dialysis). To progress further, patients must indicate an interest in learning to self-care. Specialist haemodialysis nurses support patients learning to self-care and can begin orientating the patient to the 3 level skills set of self-care haemodialysis (Figure 1: Example Self-care Skills Sheet). As a patient competency progresses to skill level 2(b)/3(a) fully self-caring at home may become a realistic option. In this small scale project we hoped to gain experiences of patient's both on full self-care and also learning to self-care dialyse. We will evaluate and learn from current service users experience and discuss issues raised in overcoming difficulties to learning SCD.

Figure 1: Example Self-care Skills Sheet from the Royal Free Hospital (see Illustrations and Figures section)

## Method

**Definitions:** Self-care dialysis (SCD) in this project was defined as those patients learning to self-care on haemodialysis within a satellite unit with potential transfer onto home-haemodialysis and those fully independent on home haemodialysis.

**Inclusion/Exclusion:** Other home and self-care modalities such as peritoneal dialysis were not included. At the time the survey was conducted 32 patients were included who were under-going SCD including those who were part way through the learning process, to those patients fully independent on HDD.

The survey was developed in partnership with the lead Clinical Specialist Nurse in Home Haemodialysis. Questionnaires focused on 3 aspects of self-care: *general questions about self-care; experiences of current support; experiences of learning supportive self-care.* Thirty-Two

questionnaires were sent out to SCD patients across 2 dialysis satellite units across North London and all patients known to be on HHD or on progression to HHD (minimum of level 2(b) competency) during November 2012. Questionnaires were anonymously completed whilst patients were on dialysis or sent to patients on HHD with freepost return envelopes.

### **Main Questions:**

1. What are the main challenges in learning self-care from a patient experiences?
2. What can we learn from those who have successfully adapted to self-care?

## **Results**

### **General Questions about self-care:**

Twenty two questionnaires were returned. Patients indicated an average overall duration on haemodialysis of 194 months. Duration on haemodialysis indicated a cluster of patients starting on self-care dialysis in the last 2 years with 2 patients having been on self-care dialysis for over 2.5 years. Three participants who have been on HD for over 12 years, only recently started SCD within the past 18 months. An average of 27 months on SCD was reported, however, the range in time since starting self-care dialysis varied with some participants only having just started SCD 2 months ago and others having starting approximately 36 months ago (see Figure 2).

Figure 2: Overall duration on Haemodialysis as a Predictor of Starting SCD (see Illustration and Figures section)

The survey reported 82% of patients described themselves as currently self-caring well or very well (see Table 1 below). This reflected how patients generally felt they had been getting on with supportive SCD. Some variation in how helpful patients considered this form of



dialysis had been for their lifestyle indicated a majority of over 70% reporting that supportive SCD had been helpful for them and their lifestyle, 23% feeling uncertain and 4% reporting the style of dialysis had been unhelpful.

Table 1: General Questions about self-care haemodialysis Questions 1b, 2 and 3 (see Illustrations and Figures section)

Two main categories were reported by twenty participants as 'easiest' and 'hardest'. These included issues around needling and relating to the dialysis machine management. Participants specified processes in needling that were hardest to deal with such as 'overcoming needle phobia'; 'putting the needle in myself' and 'deciding to try needling'. Issues related to using the haemodialysis machine highlighted areas such as 'setting up the machine/machine preparation'; 'Lining the machine'; 'Changing between machines' (e.g. between Fresenius and Braun); 'Taking themselves off the machine' and 'starting the machine after needling and ending dialysis once the machine reached final phase'. Other issues included the lack of manuals to use; 'waiting for everything to come together and 'getting control of the whole process.'

### **Experiences of current Support:**

Over 60% of patients reported that they received a lot of support from their specialist nurses, 9% reported only little support from their specialist nurses (Figure 3). One participant noted that although she did not feel her specialist nurse provided her a lot of support, she recognised that she was also not very good at asking for help when she needed it.

Figure 3: Do you feel you receive enough support from specialist nurses? (See Illustrations and Figures section)

Most helpful current support included care from specialist nurses (11 participants); family (5 participants); friends (4 participants); peer support (1 participant); email/text support (2 participants) and others included: 'improve technical support for breakdowns'; 'having a back-up carer'; 'more understanding about the machine and what causes errors'; 'preparation for home dialysis' and 'being able to dialyse at home'.

Responding to how the service could improve experiences, 17 participants responded with 47% reporting no need for improvement or that they were satisfied with their experience. Other practical issues arose: ensuring nurses prepare enough solutions and concentrates; that equipment is in place before a patient arrives for dialysis; allocated self-care areas with dedicated self-care machines. One participant suggested that each dialysis site had one nurse dedicated to helping supported SCD patients whilst they dialysed. This would prevent feeling isolated in being left to deal with problems alone whilst nurses attend to non-SCD patients. Supporting re-housing as a priority was suggested so that patients could dialyse from home. Lastly one participant stated that their experience would only be improved if they could stop self-caring.

### **Experiences of learning supportive self-care dialysis:**

When asked what helped the most during the learning process nurses were identified as the main support. Other resources and skills participants turned to fell into 4 main categories: Nurses, Participant own strategies and tools, learning aids and other support (see Table 3).

Table 3: What helped you the most when learning how to self-care on haemodialysis? (See Illustrations and Figures Section)

Similar to problems reported in Table 1, challenges fell into two main categories; Issues with needling and issues with the dialysis machine (Figure 4). A further question explored whether needling themselves was an issue.

Figure 4: Some people can have problems with specific areas such as preparing access and learning how to do needling. What did you find most challenging? (See Illustrations and Figures section)

Exploring specific problems, 12 participants found needling problematic, 7 participants reported no problems and 2 participants were continuing to use a line and had not attempted to needle. Further inquiry highlighted 'Practice' (e.g. "trial and error"; "Practicing and encouragement from nurses"); 'Management of Pain' (e.g. "It was scary, I put Emis (topical anaesthetic cream) so I don't feel the pain"); and "By waiting until fistula site worn in (no longer pain on entry of needles))" as the main skills used.

Participants raised in fairly equal numbers that more information would have been helpful, to have spoken to other patients (via phone/email/face to face) or observe others. Other comments included: "Have step by step instructions for reference"; "Provided more information pre AND post dialysis"; "Provided DVD of fistula patient being connected and disconnected" and "Having written information on the process of preparation".

## Discussion

The survey provided an evaluation of the support provided to patients currently learning SCD. General feedback indicated good support and provided an overall positive stance to self-care. Re-occurring challenges prevented progression up the self-care skills set toward full independence on dialysis and how to overcome them need further exploration. Issues to consider for SCD programmes are discussed below.

## **General questions about self-care**

It is positive to hear participants report highly of their nursing support staff. It is important to note that the survey was carried out on a small service where staffing resources were at the time able to cope with providing more one to one care to the numbers of patients learning to self-care; particularly in the latter stages of becoming fully independent. Figure 2 highlights the more recent drive to increase patient numbers on the programme. Factors influencing this trend include how self-care options are promoted to patients and increases in resourcing for home dialysis equipment. Overall, the results highlight how well patients have been coping once in the self-care programme and that the majority have found this modality very helpful.

## **Experiences of current support**

Current support is heavily reliant on specialist nurses. Although current reliance on nursing support appears to work effectively, as the service grows there is a need to widen the availability of resources and support. This may be similarly reflected in other SCD programmes across the country. Successful models of HHD programmes have (Kidney Health Australia, 2012; Agar, 2008; Honkanen & Rauta, 2008) highlight the importance of well-developed training networks (Honkanen & Rauta, 2008); best practice incorporating home visits and other follow up options including casual phone calls; email or electronic support; teleconferences and tele-monitoring; clinic technique assessments; on-call technical and nursing support; peer support groups; nephrology and other allied health visits to name a few (Kidney Health Australia, 2012).

## **Experiences of learning supportive self-care**

Responses in table 3 enable supportive-self-care programmes to think toward future developments. Access to the main sources of support (Nurses, Participant own Resources and Learning Aids) could enrich patient experience and learning for both current

and future self-care patients alike. Multidisciplinary working (i.e. with Social Workers and Health Psychologists), structured training for specialist nurses may improve consistency, and psychosocial skills required to support patients learning SCD.

**Nurses:** Reinforcement models in training (e.g. Orem's theory) can remind clinicians to use these to plan patients' progress. By also integrating psychological theories such as 'Self-Determination Theory' (SDT) and the use of communicational skills of Motivational Interviewing (MI) in training programmes, clinicians can help patients' foster self-motivation for new behaviours (Markland, Ryan, Tobin, Rollnick, 2005). SDT postulates that behaviours lie along a continuum reflecting the extent to which a person fully endorses and commits to what they are doing. Supported by this underlying theory MI can help individuals develop clear appropriate goals, provide positive feedback and support self-efficacy to enhance patients feeling of competence (Markland, Ryan, Tobin, Rollnick, 2005). MI has been investigated in a range of healthcare settings including diabetes (Channon, Smith and Gregory, 2003; Clark and Hampson); smoking (Ershoff et al, 1999); adherence (Konkle-Parker, 2001; Schmalting et al, 2001; Smith et al, 1997); cardiac rehabilitation (Hancock et al, 2005) and also Chronic Kidney Disease management (Martino, 2011).

**Patients own Resources:** Clinicians who can integrate MI as a mode of communicating with patients learning SCD can facilitate positive behaviour change through empowering confidence, self-efficacy and enabling patients to work at their own pace. Other personality factors to consider suggest both emotional stability and conscientiousness determine self-care indirectly (Skinner et al's (2002) through personal model beliefs (Leventhal, Nerenz, Steele, Taylor & Singer, 1984). Conscientiousness in particular has been associated with better self-care for those on renal dialysis (Christensen & Smith, 1995). Aligning MI goals with patient personal values may help patients desire for better self-care and interdisciplinary working with psychologists can help support patient emotional stability.

Learning Aids: Learning aids and tools (e.g. books, manuals, and workbooks for patients to keep their own notes when learning) can be made more available for patients learning SCD; enriching learning opportunities through observation of nurses and discussions with other self-care dialysis patients.

**Peer and Family Support:** Reports of peer and family support concur with research documenting the positive effects of social networks and social support on a variety of chronic illness outcomes (Christensen & Smith, 1995). Gallant (2009) supports the finding that increased social support, particularly disease or regimen-specific support are related to self-management behaviours. There is much scope for developing peer support systems e.g. ‘buddying’ patients with more experienced SCD patients and psychoeducational groups for patients and families together (Wong, Dixon, & Cove, 2011).

Needling and issues specific to the haemodialysis machine: Despite previous assumptions of barriers, (Hope 2013; Cafazzo, Leonard, Easty et al 2009; Ledebro 2008; McLaughlin, Manns, Mortis et al, 2003) self-cannulation is not only reported by patients as the biggest or hardest challenge, however, needling is still a problem for many. The survey helped to build a picture of some of the challenging steps (‘deciding to try needling’; ‘overcoming needle phobia’; ‘putting the needle into myself’; and ‘managing pain’). Research in this area is scarce with few papers exploring the patients’ perspective. With a 30 year career as a nephrology nurse and a broad experience of dialysis and SCD as a patient, Cate Lewis (2011) shared experiences as both clinician and patient but more research is needed to explore the psychological breakdown of the process of cannulation.

Similarly, few studies examine the use of the HD machine for self-care. Nursing experiences of renal technology and how patient/nurse relationships are impacted have been explored (Bennet, 2011a; 2011b; Polaschek; Bevan, 1998). Lehoux, Sait-Arnaud and Richard (2004) explored the advantages and drawbacks of technology and its impact on patient participation in the social world but there is no specific research exploring patients’ use of HD

machines on SCD, indicating the need for future research. In one discussion with a SCD patient following the survey, the innovative idea of a patient written manual for using dialysis machines was raised. It could explore common problems, touch on subjects that patients may be anxious with dealing with on the dialysis machine and how one can overcome them. The survey was a small project sampling only a small number of patients, however, useful issues and research questions have been raised which can further our work in improving self-care services. A list of suggested recommendations is outlined from this survey below:

Figure 5: Suggested recommendations for self-care haemodialysis services to consider (See Illustrations and Figures Section).

### Key point sentences

- Barriers and challenges have been explored the most in research into self-care dialysis however not enough discussion on how to improve and overcome specific challenges within the process of learning.
- Challenges faced by majority of patients include issues with self-cannulation and issues with the dialysis machine.
- Challenging steps of needling include 'deciding to try needling'; 'overcoming needle phobia'; 'putting the needle into myself'; and 'managing pain'.
- No research has looked at challenges with using the dialysis machine and this should be explored further.
- More consistently provided access to learning aids and nursing support can improve self-care programmes through opportunities to learn through educational programmes, observation of nurses and peers and written material.

- Further exploration into personality factors and patients own resources may help clinicians to tailor learning approaches to patients.
- Current support is heavily reliant on specialist nurses however with growing services this is unsustainable



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# Supporting Patients Better on Self-Care Haemodialysis:

## Illustrations and Figures

**SKILL ASSESSMENT**

Skills	Learning Start date	Things to improve	Competent Date and Signature	Level
Infection control Hygiene Washing hands				1
Take and record the weight, blood pressure and pulse				1
Complete required entries on dialysis chart				1
Machine On, Choose bi bag, correct concentration and dialyser				2 (a)
Prepare pit on pack				2 (a)
Testing, filling and Priming of the dialysis machine				2 (a)
Insert the correct data				2 (a)
Preparing access (AVF or Line)/ Needling				2 (b)
Line care/ Dressing				2 (b)
Commencing dialysis				2 (b)
Ending dialysis Washing back				3 (a)
Finishing the care of AVF or Line				3 (a)
Strip and disinfect the machine post hd				3 (a)
<b>Problems During Dialysis</b>				
Arterial Venous pressure				3(b)
Dialyser alarm				3(b)
TMP				3(b)
Air in the line				3(b)
Blood leak				3(b)
Bleeding				3(b)
Clogging				3(b)
Low BP				3(b)
Function of the kidney and hdy				3(b)

Level 1= Basics; Level 2=Intermediate; 2a - Machine Preparation; 2b - Access Use, Care & Connecting; Level 3=Advanced; 3a- Taking off; 3b Troubleshooting

Figure 1: Skills Assessment Sheet

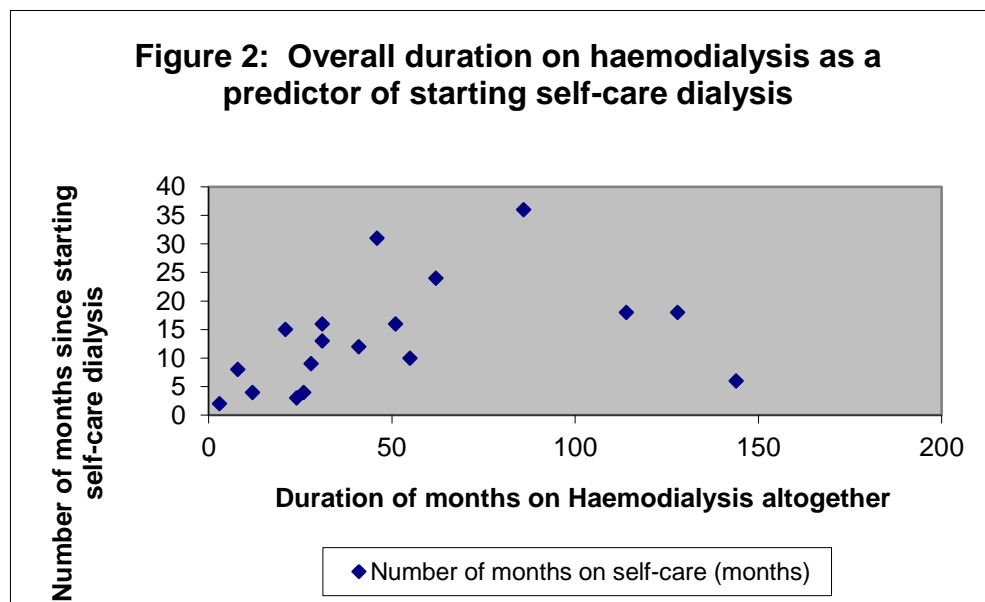
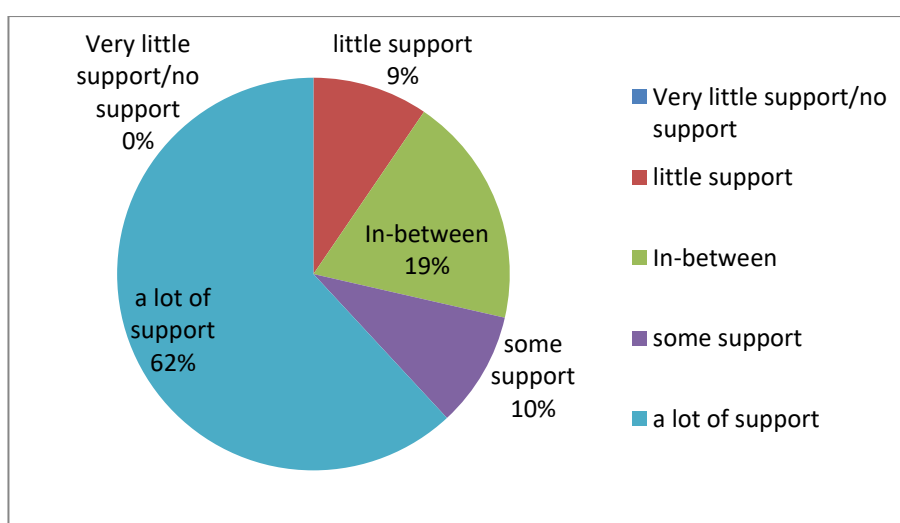


Figure 2: Overall duration on Haemodialysis as a Predictor of Starting SCD

	1b. How well do you think you are self-caring now?	2. How well do you generally feel you have been getting on with supportive self-care dialysis?	3. How helpful has this form of dialysis been for you and your lifestyle?	
<b>Very well</b>	50%	50%	<b>Very Helpful</b>	64%
<b>Well</b>	32%	36%	<b>Helpful</b>	9%
<b>In-Between</b>	18%	14%	<b>In-between</b>	23%
<b>Poor</b>	0%	0%	<b>Unhelpful</b>	4%
<b>Very Poor</b>	0%	0%	<b>Very unhelpful</b>	0%

*Table 1: General Questions about self-care haemodialysis Questions 1b, 2 and 3*

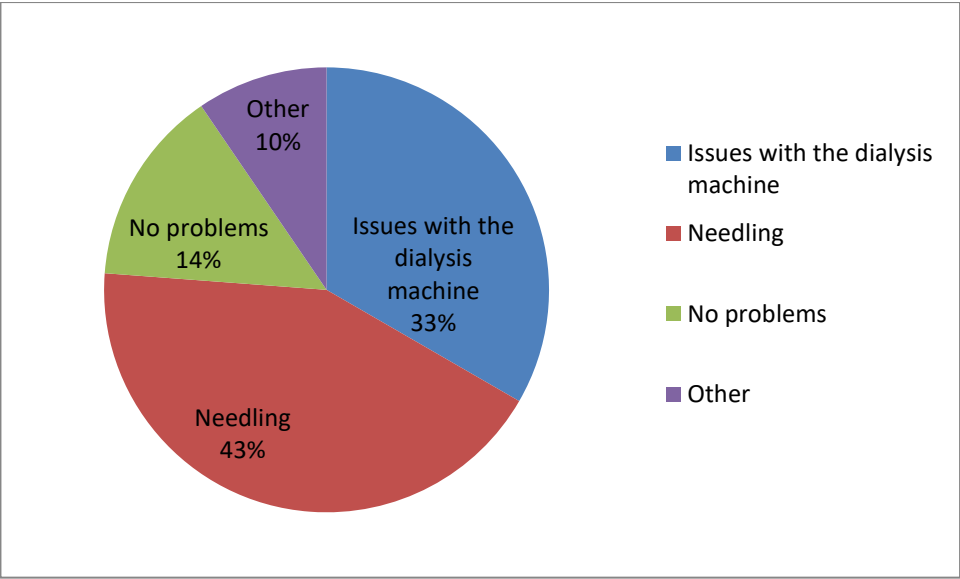


*Figure 3: Do you feel you receive enough support from specialist nurses?*



<b>Nurses</b>	<b>Participant's own resources</b>	<b>Learning aids</b>	<b>Other support</b>
Patient nurses	Confidence	Information gathering	Peers: Having other people learning self-care at the same time
Encouragement from team	Experience (participant was previously a home haemodialysis patient)	Reading books	Family encouragement
Not feeling under pressure	Learning at own pace	Taking notes when possible and writing notes up into a document	
General good support	Time and repetition	Getting to know everything on the dialysis machine/learning about the dialysis machine	
Nurses going through the process in a step by step fashion Good teacher Thoroughness Spending time talking to the nurses		Observation of nurses	

*Table 3: What helped you the most when learning how to self-care on haemodialysis?*



*Figure 4: Some people can have problems with specific areas such as preparing access and learning how to do needling. What did you find most challenging?*

Recommendation	Further points
Nurses are invaluable but how services distribute their roles must change with increasing uptake of dialysis and the need to improve SCD	Dedicated SCD nurses readily available for self-caring patients at each satellite site.
Standardise programmes for education and learning	Up to date training for specialist dialysis nurses Involve behaviour change and psychological methods in training such as Motivational Interviewing for health care professional Involve patients in learning and teaching others Post dialysis education
Make use of the full multidisciplinary team	Social Workers can prioritise re-housing needs Involvement of psychologists can aid education, training and overcoming patient anxieties throughout the self-care process
Develop peer support systems	Experienced self-care dialysers can help support new SCD learners. Buddying/peer support programmes.
Widen other resources	Standardised manuals e.g. step by step guides The Alternative guide (written by patients) Making more use of observable resources e.g. observing peers, nurses and watching DVD's

**Figure 5: Suggested recommendations for self-care haemodialysis services to consider**

## **Title: Self-Cannulation – Exploring the Process**

### **Abstract**

Self-cannulating can have several advantages for patients including creating active involvement of patients in their own care and preservation of vascular access. Despite the advantages, self-cannulation can often be the main reported reason for not learning self-care haemodialysis. This perspective article presents an examination of the self-cannulation process as part of the wider issue of self-care haemodialysis. It reviews current medical and psychological literature exploring barriers in the journey for a patient from creation of Arterial Vascular Fistula through to the pain involved in the action of needle-insertion. Through breaking down the components of the process, it highlights several gaps in current research and potential areas for psychological intervention to better support patients who may potentially learn self-care haemodialysis in the future.

### **Introduction**

Haemodialysis continues to be the most widely used treatment modality (Castledine, Gilig, Rogers et al, 2010). There is also increasing evidence which supports the extension of self-care haemodialysis and home based haemodialysis (Jayanti, Foden, Wearden et al, 2015) and some studies reporting better health-related quality of life with self-care dialysis modalities (Manns, Johnson, Taub et al, 2003; Kutner, Zhang, Barnhart et al, 2005). However, uptake of home-based dialysis continues to be low (Blake 2000; Jiwakanon, Chiu, Kalantar-Zadeh & Mehrotra, 2010; Mendelssohn, Mullaney, Jung, Blake & Mehta, 2001).

Self-cannulation or ‘needling’ can often be the central focus for both clinician and patient in home haemodialysis (Verhallen, 2013) and the main reported reason for not using self-care haemodialysis by professionals and non-self-care patients alike. Patients who are able to self-cannulate are often seen as the best candidate to needle themselves. Self-cannulating patients have several advantages; the patient is always present to carry it out, it

can actively involve patients in their own care and can help preserve their own vascular access site (Brouwer, 2011). Mott (2010) adds that self-cannulating patients are able to feel both ends of the needle and therefore can tell when the tip of the needle is in the vessel. Techniques such as buttonhole (BH) methods and the rope ladder technique are often discussed in terms of which provides better outcomes for patients adjusting to self-care haemodialysis (Evans, 2012; Mott, 2010; Verhallen, Kooistra & Jaarsveld, 2007). No paper has discussed the psychological breakdown of processes involved in self-cannulation. In a survey carried out by Wong, Walker, Cove, Pires-Yfantouda, (2015) some of the challenging steps of needling reported by patients included 'deciding to try needling'; 'overcoming needle phobia'; 'putting the needle into myself'; and 'managing pain'. This article will attempt to investigate some of these issues further in hope that some understanding of the psychological processes involved can assist self-care learning programmes and prompt important future research.

### **Arterial Vascular Fistula's (AVF's)**

The process of Haemodialysis requires access to an individuals' vascular system. A surgically created Arterial Vascular Fistula (AVF) is usually created as opposed to a vascular catheter to reduce the risk of death, infections and cardiovascular events (Ravani, Palmer, Oliver et al, 2013). An AVF is an important component of the self-care haemodialysis process but establishing and maintaining a vascular access can be one of the biggest problems in haemodialysis (Bonello, Levin & Ronco, 2004). One of the first challenges to self-care home haemodialysis is therefore the establishment and maintenance of the AVF. Patients are required to continually monitor the fistula, as its care and protection are vital to the fistula's survival (Richard & Engebretson, 2009).

A fistula is created surgically and the development of a fistula enables arterial blood flow into a vein that subsequently becomes arterialised. It can take approximately 1 to 4 months to mature before it can be used for haemodialysis (Besarab, 2004). As a fistula

matures and the vein arterialises, it becomes thicker and enlarges, becoming visible on the skin surface as a raised area on the skin. Patients are required to carry out arm exercises such as squeezing a rubber ball daily and regularly to enhance maturation (NKF, 2006). Once the vein has matured and is safe for cannulation i.e. able to tolerate 500 to 600 ml/minute (NKF, 2006; Allon & Robbin, 2002), it can be cannulated or venepunctured, usually with two large 14-16 gauge needles (Richard & Engebretson, 2010).

**AVF self-care:** Monitoring and maintenance care of the fistula is continuous and includes patients' familiarity to detect slight changes e.g. feeling for pulses and a thrill (vibration) around and over the fistula, respectively, assessing blood flow and patency; as recommended by The American Nephrology Nurses' Association (ANNA, 2006), Centers for Medicare & Medicaid Services (CMS, 2004), Fistula First (2006), NKF (2006), and the Vascular Access Society (n.d). Patients are asked to keep the fistula protected from pressure and injury (including pressure from restrictive clothing), the area clean and regularly assess for infection, prevent lifting heavy objects, and prolonged bending of the extremity.

A patients' journey in taking control of their treatment through to self-care haemodialysis therefore starts with accepting and living with an arteriovenous fistula. Richard & Engebretson (2010) explored patient experiences of deciding to live with an AVF for haemodialysis and found an overarching theme of vulnerability with an underlying theme of body awareness. Bodily awareness was related to the patients' experience of symptoms prior to starting dialysis, prompting them to seek treatment. Patients highlighted that an element of trust was required for the creation of vascular access with dependence and mistrust of providers causing hesitation. Unsurprisingly several patients in the study felt vulnerable when providers had difficulty with cannulation of the AVF, similar to Hagren, Pettersen, Severinsson, Lützen, and Clyne (2001; 2005) findings. It would therefore be anticipated that if patients feel insecure when a 'professional' cannulates them, they may also feel fearful of self-cannulation and fully taking responsibility themselves. Richard & Engebretson (2009) found that self-

cannulation can bring about feeling less dependent and mistrusting of providers, more autonomy and a greater sense of control with self-care. Additional evidence indicated that self-cannulating patients helped with pain, missed venepunctures decreased along with haematomas, scaring and aneurysm formation (Verhallen, Kooistra & van Jaarsveld, 2007). It is possible that early development of patient independence and control could potentially influence self-confidence in being able to self-cannulate. Education programs specifically geared toward enhancement of the elderly's mastery over their lives and behaviours have shown to promote a sense of independent living in older people (Searle, Mahon, Iso-Ahola, Sdrolas, van Dyck, 1995) and thus physical and psychological empowerment. Similar types of psychoeducation programmes provided early in a patients' renal health journey may also influence physical and psychological empowerment, encouraging independence and control over their fistula and renal self-management.

### **Deciding to try self-care haemodialysis and self-cannulation**

Clinical guidance in the US, Canada, UK, Europe and Australasia suggest treatment options for Chronic Kidney Disease include the preference of a fully informed patient (Hornberger, Habraken, Bloch, 1995). Morton, Tong, Howard, Snelling & Webster (2010) suggest from their systematic review and thematic synthesis of qualitative studies, that experiences of other patients are a great influence in decision making of individuals and carers, where timing of information is also of particular importance. Tong, Palmer, Manns et al (2013) went further in investigating beliefs and expectations of home haemodialysis from patients and caregivers themselves. Both positive and negative themes emerged from their qualitative study, with the negative theme focusing on 'disrupted sense of normality'; 'family burden' (i.e. onerous responsibility, caregiver uncertainty and panic and visually confronting); 'Housing constraints' and 'healthcare by 'professionals' not 'amateurs' (including isolation from peer support). Positive themes of flexibility and freedom; comfort in familiar surroundings and

altruism were overshadowed by negative themes and an overall feeling that home haemodialysis would be an overwhelming physical and emotional burden. Lack of confidence and inability to accept the medical responsibility of managing any potential complications of dialysis fed into feeling emotionally overwhelmed.

Decision making therefore presents its next challenge on the path to self-care haemodialysis. In moving toward, a more self-care approach, a stepped approach could be taken where patients proceed through a series of 'self-care steps' e.g. through hand hygiene practice, lining and prepping the dialysis machine to preparing access and needling (Wong, Walker, Cove, Pires-Yfantouda, 2015). Therefore a further decision making step is required to actually decide to try needling itself.

Charles, Gafni and Whelan (1999) explored decision making in the context of life threatening disease where several treatment options are available with different potential outcomes such as benefits and risks, side effects and varying impact on the individuals' physical and psychological wellbeing. The outcomes in each individual's case were posed as uncertain. Charles et al (1997) argued that shared treatment decision-making could be identified by reference to four characteristics:

1. At minimum, both physician and patient are involved in treatment decision-making process.
2. Both the physician and patient share information with each other.
3. Both the physician and patient take steps to participate in the process of decision-making by expressing treatment preferences.
4. Both the physician and patient are in agreement of a treatment to implement.

Charles et al (1999) add to these steps by discussing 'analytical stages' of 'information exchange'; 'deliberation' and 'deciding on treatment to implement'.

In the 'information exchange' component Charles et al (1999) emphasise that exchange of information is a process enabling the physician and patient to build rapport and



get to know each other, which is particularly important for the patient. For the patient, it is an opportunity to assess the physicians practice style, attitudes and behaviour, checking if it matches their own preferences and expectations. Thus building trust is part of the process.

‘Deliberation’ refers to the process of being able to express and discuss treatment preferences within the physician-patient relationship. In a shared model, both parties (physician and patient) are assumed to have an investment in the treatment recommendation to patients and thus to attempt to persuade the other to accept the recommendation. This is only possible if physicians can also concentrate on listening to and understanding why an individual might favour a different treatment option. However, Charles et al (1999) illustrates how they describe only one small component of a larger decision-making process involving several others in key positions outside the medical encounter. Finally, ‘decision on the treatment to implement’; both physician and patient have an investment in the ultimate decision made through the process of deliberation.

It is important to recognise that where decision making research such as that described above is very useful in thinking about how health care professionals can put into practice discussions for decision making; research is not specific to decision making to self-cannulate. Indeed, it is not known how often these discussions currently take place when initially introducing the idea of self-care haemodialysis. Charles et al (1999) conclude that “treatment decision-making is a complex process that takes place over time and can involve many individuals rather than an event that takes place at a fixed point in time and is restricted to the physician-patient dyad”. This suggests that decision-making is a changeable process over time. In the context of deciding to self-cannulate it indicates that this is a decision that requires discussions at several time-points and with careful sharing of information from a variety of health care professionals, family, friends and possibly including discussions with other patients.

## Needle Phobia

Anxieties related to blood and injections are common in medical settings with 10% of individuals reporting an excessive fear of needles causing significant avoidance, distress and/or impairment (Deacon & Abramowitz, 2006). Needle phobia itself is characterised by an intense and persistent fear of injections affecting approximately 1.6% in the general population (Bienvenu & Eaton, 1998) which is often associated with feeling faint upon exposure to the feared stimuli, creating a vasovagal syncope experience or fainting. Several demographic and psychological characteristics have been associated with needle fear and vasovagal reactions e.g. a younger age; lower body weight; and first time donor status are all significant predictors (Newman, 2003; Trouem-Trend, Cable, Badon, Newman & Popovsky, 1999). Whereas psychological factors such as blood and injury fears and pain sensitivity appear to predict vasovagal reactions more strongly than demographics (Meade, France & Peterson, 1996). Indeed 'fear of fainting' can additionally contribute to needle fear (Kleinknecht and Lenz, 1989).

Deacon & Abramowitz (2006) indicate that despite increased understanding of the prevalence and associated features of needle fear and the physiological reaction, studies have primarily been conducted in non-medical settings, blood donor settings with healthy participants. Thus the generalisability of current research is questionable and it appears that relatively little is known about typical experiences of individuals in medical settings. Deacon and Abramowitz (2006) also suggested that with small needle size and small amounts of blood collected in these research contexts, with relatively brief exposure to the needle, this impacted on a lessened anxiety and vasovagal reaction than potentially would be seen in other contexts.

In contrast, haemodialysis needles are known to be both bigger in length and width. Pergolotti, Rich and Lock (2011) explored the effect of the buttonhole method on needle stick pain and anxiety, generally finding that the mean pain and anxiety measurements were significantly lower with the use of buttonhole method, regardless of the use of anti-anxiety,

analgesic, or blood-thinning medications. However, it is clear that more research is needed in the area of needle anxiety within the context of self-cannulation for haemodialysis as this presents a very different context and situation to needle phobia which has been researched in 'general health' populations and does not account for the uniquely sized needles used within haemodialysis. Additionally, needle anxiety is regularly reported as a reason for the low levels of self-care haemodialysis, yet there is little concrete evidence of how many individuals report this and why. Thus a much stronger evidence base is required to further explore this area so that patients can be best supported with any potential anxiety relating to haemodialysis needles. Despite the lack of evidence, there is a potential need for psychological intervention to support and manage prospective self-cannulating candidates with anxiety related to needles. Jenkins (2014) sets out in detail the usual course of Cognitive Behavioural Therapy (CBT) for a patient facing needle phobia, whilst having awareness of managing anxiety and maintaining arterial pressure to minimise the patients' likelihood of fainting. CBT has a strong evidence base for use within anxiety and phobia related disorders and may therefore be a useful psychological intervention for patients struggling with anxiety related to needles.

### **Pain and anticipation pain**

Pain is defined as a subjective, sensitive and emotional experience, usually in relation to past experience within a given situation (Innis, Bikaunieks, Petryshen, Zellermeier & Ciccarelli (2004); Vascular Access 2006). Figueiredo, Viegas, Monteiro, Carlos, Poli-de-Figueiredo (2008) state that repeated puncturing of the AVF can lead to fear, anxiety and a considerable degree of pain. Figueiredo et al (2008) suggests that the most frequent cause of pain for haemodialysis patients is needling and that the level of pain experienced may be due to the calibre and length of the fistula needles. Furthermore Bay, Cleef & Owens (1998) found that patients rank pain during needle insertion as most commonly problematic in dialysis vascular access. Very few studies have explored the problem of pain during needle insertion in

haemodialysis patients, however, a few studies (e.g. Ball, 2006; Verhallen, Kooistra & Jaarsveld, 2007; Murcutt, 2008) have suggested that the introduction of the buttonhole technique has been beneficial for patients reporting reduced pain. Figueiredo et al (2008) measured pain associated with AVF needling in 47 patients, using both button hole technique (in 40% of participants) compared to traditional rope ladder technique (in 60% participants). This again indicated a slightly lower degree of pain via button hole technique (mean  $2.4 \pm 1.7$ ) compared to conventional rope-ladder technique ( $3.08 \pm 2.28$ ). The difference was not significant ( $p=0.128$ ) however indicates some difference even within a small sample. Nevertheless exploration of pain during haemodialysis and particularly AVF needling is rare in research and currently limited (Crespo, Rivero & Contreras, 2004; Ball, 2006; Verhallen et al, 2007). Thus pain perceived during cannulation continues to be an unresolved problem for dialysis teams and lacking in both clinical and psychological knowledge as to how to support patients experiencing pain during cannulation better. Figueiredo et al (2008) suggests that one strategy that can be used by nurses or health care staff carrying out needling can be to use a more positive approach to patients before needling. They suggest the use of more positive language and to bear in mind the variety of biological and environment factors that can influence patients' pain experiences.

With the current research that has been carried out in mind, it is clear that with such limited understanding of how to manage AVF cannulation pain and anxiety during haemodialysis when 'experts' such as health care professionals are carrying out the needling, it may therefore be difficult to firstly suggest that self-cannulation is a good option and to teach methods to minimise pain to patients themselves. It may be that lessons can be learnt from patients who have already agreed to self-care haemodialysis and trained to self-cannulate, as they are most likely to understand the experience and how to individualise self-cannulation methods to suit a person best. Lessons can possibly be learn from psychological treatment packages based on CBT for paediatric pain management (Elliot & Olsen, 1983; Jay, Elliott,

Ozolins et al, 1985) involving a combination of modelling, relaxation training, guided imagery or distraction, graded exposure or active behavioural rehearsal and reinforcement scheduling (Duff, 2003).

## Patient Experience

Purves (2015) explored patient experience with home haemodialysis finding that self-cannulation was the second most common barrier emerging from interviews with patients. Self-cannulation was a recurrent theme running throughout Purves qualitative analysis. It was a highlighted issue for participants choosing their vascular access as a consequence of the physical pain and process of needling. Despite recommendations of an AVF creation prior to starting haemodialysis (Ravani, Palmer, Oliver, Quinn, MacRae, Tai et al, 2013), helping to reduce complication rate, participants in Purves (2015) study were more likely to report a central venous catheter as their preferred method for vascular access due to it not requiring needling. If needling did occur, Purves (2015) found that participants were more likely to rely on carers to perform the act of needling. From individual participant quotations from the study, it was highlighted that the pain was most specific to the needle piercing the arm and getting through the flesh rather than hitting the actual access.

The impact of self-cannulation on choice of vascular access also showed a negative influence on participants' self-efficacy. On the other hand, central venous catheter was associated with improving ones self-efficacy in Purves study (2015) thus resulting in the underutilisation of AVF's (McRae, Ahmed, Atkar & Hemmelgarn, 2012). Cafazzo, Leonard, Easty, Rossos and Chan (2009) found that patients can feel overwhelmed by the multiple tasks of learning dialysis and can lack confidence in self-cannulating. Similar themes have been found in previous research on haemodialysis and self-cannulation (Cafazzo, Leonard, Easty, Rossos and Chan, 2009) and more recent studies (Taylor, Hanson, Casey, Craig, Harris & Tong, 2016), all suggesting that a large number of participants felt anxious, unable to self-canulate

and thus cannulation was often left to carers. Taylor et al's (2016) study participants suggested that to improve access, reducing the number of needles required would improve self-cannulation. This advocates for the use of the buttonhole method of cannulation or continued use of central venous catheter.

## Conclusion

It is clear that the psychological barriers to self-cannulation and anxiety associated to needling occurs not just at the point of cannulating but once the patient has chosen haemodialysis as a renal replacement therapy. A number of themes are raised throughout the self-care haemodialysis journey such as confidence, body image, anxiety, needle phobia, self-efficacy. This encourages thought into how psychological interventions might be able to support the self-care haemodialysis process. For example, early psychoeducational programmes targeting independence and control, influencing psychological and physical empowerment, or more direct and specific interventions targeting needle related anxiety and pain. There may be ongoing issues requiring periods of psychological support such as adjustment and physical bodily changes resulting in a need to adapt to body image difficulties.

Fear and pain anticipation are regular occurrences for patients from the start, regularly interfering with decision making relating to renal replacement therapy choices and influencing clinical barriers to both haemodialysis, self-care haemodialysis and self-cannulation. Several areas of future research have been highlighted in this article including research looking into pain and needle phobia specific to haemodialysis. These areas are particularly important to look into for further understanding of both clinical and psychological processes of self-care haemodialysis. Taylor et al (2016) highlights the importance of interventions with a psychological focus alongside clinical interventions such as buttonhole method of cannulation and use of anaesthetics. They suggest that strategies such as distraction (Ball, 2005) and music therapy (Pothoulaki, Macdonald, Flowers et al, 2008) may be helpful and counselling to

support anxiety during the process, however this lacks evidence. To encourage uptake of self-care haemodialysis patients need to be supported better early on within education, decision making and training needs for a less anxiety provoking and overwhelming journey to home-based dialysis.

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# **SECTION C: PROFESSIONAL PRACTICE**



## **CORE UNIT 1: GENERIC PROFESSIONAL COMPETENCE**

### **Unit 1.1 Implement and maintain systems for legal, ethical and professional standards in applied psychology**

Healthcare is a very personal issue which once publicly known can have implications on many areas of life including employment, society's view of and individual access to services and family life. It is a key skill to be able to adequately learn to work within the health systems security and controlled system for managing information for the protection of the patient and this is stated as a requirement of the Health & Care Professions Council (HCPC) and therefore key learning for me on the health psychology doctorate. An expected requirement once employed within the NHS was to complete mandatory training which involved a full understanding of patient confidentiality, how to keep patient notes confidential and safe and how to store confidential notes. Once employed as an Assistant Psychologist I also completed mandatory training for the trust and continued to 'update' components of training annually.

An additional level of confidentiality, security and control of information is required for psychologists. This is stated as a requirement within the British Psychological Society (BPS) ethical guidelines for psychologists. As mental health is a very sensitive issue and public knowledge of one's mental health can have possible discriminatory consequences. Therefore as psychologists working within physical health additional layers of confidentiality and record keeping are required within the wider multidisciplinary team a psychologist may be working within and awareness that not all information will be disclosed to other health care professionals or information will only be shared on a "need to know basis".

Working in End Stage Kidney Disease and Liver Transplant often brought up issues of confidentiality and cases where an additional layer of confidentiality was required from the health care team. I would often provide the wider health care team with routine transplant assessments and run parallel clinics with the 'low clearance' nurses (low clearance being

patients with low level functioning kidneys which have not yet reached renal replacement therapy). This would require communication of patient information from the assessment to the physical health care clinicians about transplant understanding, readiness or motivation to have a transplant, or adjustment, understanding of illness and indication of any mood disorder. Patients would have consented to this type of assessment and have a clear understanding that certain information regarding their health would be communicated to their doctors or nurses. However with more in depth information, I learnt to be more careful about disclosing personal and more sensitive information. In addition to these standard clinics, as part of the psychology service, I also provided individual ongoing therapy to patients where patients may disclose more personal experiences (such as within the behaviour change competency). These types of information were not necessarily pertinent to the patients' health problem and thus I would make a decision not to disclose this information to other health carers. Within Clinical Health Psychology we also kept records of case notes separate from the regular physical health record keeping.

These record keeping and confidentiality principles and practices were also maintained when keeping notes and patient details whilst running 'Mind and Body Matters' for the consultancy competency and when collecting data for the research competency in Liver Transplant.

Within the research component in particular it was mandatory to apply for and receive NHS ethical approval before beginning recruitment for the research study. This is a process whereby research proposals are carefully scrutinised to ensure they meet ethical standards of recruitment and methodological procedure for research within the NHS that may be using NHS patients or NHS patient data. Prior to beginning the research component and my study in Liver Transplant NHS ethical approval was met by Harrow Research Ethics Committee (see Appendix 1). Furthermore due to difficulties in recruiting fully from an NHS cohort I also later sort approval from university ethics for Internet recruitment. Although eventually this

was not required, it demonstrates the importance of being mindful of all ethical practices when recruiting for research, not just NHS patients. The process of applying to both NHS and university ethics helped me to further my understanding of the ethical implications that need to be considered when carrying out research. It highlighted the need for patient confidentiality and consent. Patients needed to also be informed that participation (or not participating) would have no impact on their ongoing patient care. I had to also be mindful when and how to approach patients for recruitment and the process of carrying out interviews with patients who had ongoing health problems. Further ethical approval for Internet recruitment ensured that I understood the ethical implications of the use of technology, advertising and recruiting from Internet.

Additional legal guidelines are provided by the department of health to provide rules on keeping patient notes and records during and following any research involving NHS patients (see appendix 2). Therefore for long term storage a locked filing cabinet was obtained to store research patient records within an office in the hospital.

## **Unit 1.2 Contribute to the continuing development of self as a professional applied psychologist**

When starting training it was difficult to know which areas to start to work on for my professional development. There were many areas I wanted to develop due to my lack of experience in the field of health psychology and it was hard to know where to begin and where my skills specifically lacked. I used the resources that were already available to me though the university and my work place. For example from a more academic perspective, the doctorate training, through the university's monthly workshops dedicated to the core unit competencies (such as, consultancy, teaching and training, behaviour change and research components), was required to be completed as part of the training. This enabled me to use the workshops as a starting point for increasing my knowledge and skill development. The behaviour change

competency was where I felt that I had the most experience and therefore a good place to start to initially build my confidence. Prior experience working with mild to moderate mental health problems meant that I had already developed some understanding and knowledge of working individually with patients to change unhelpful behaviour. However I also realised that there were some areas that I needed to increase my awareness and experience. For example, I had worked with mild to moderate mental health however my current placement in end stage kidney disease and liver transplant required an understanding of how to apply individual behaviour change interventions to an older population with long term health conditions such as kidney disease and develop my skills for best practice within this area of intervention. Therefore there were two areas that I felt I needed to build my knowledge within; working with older adults; and working with long term conditions. I sort out training within these areas and found that internal training held by the trust provided additional skills in "CBT for older people with long term condition". This fulfilled the exact criteria for developing the areas I required. Additionally through observations and working alongside my clinical supervisor especially within the first few months of starting the position as an assistant psychologist I started to gain a deeper understanding of the illness specialisms where I was working (within end stage kidney disease and liver transplant).

Through experience and gauging my confidence in different areas of clinical and academic work I was able to monitor my own abilities and development. From both clinical and academic supervisors I gained a further sense of what I needed to work on for my professional development. The annual reviews were also useful for feedback and monitoring development. It provided time for personal reflection of the year on what improvements were required.

The consultancy provided me the opportunity to develop my experience of project management and health prevention and protection interventions on a slightly larger applied scale than the individual behaviour change. Whilst implementing the consultancy I sought

further experience in Behaviour Change Intervention design and evaluation through day workshops provided by the British Psychological Society. Additionally I would use learnt research skills and supervision to inform practice on an individual clinical level with my patients and also to provide summaries of research on various related health issues (obesity and diabetes related to end stage kidney disease) to the wider multidisciplinary team.

Two of my weakest areas where I felt I had the least confidence and minimal amount of experience included teaching and training and systematic reviews. Where teaching and training was very much about developing confidence and experienced, I developed these skills through exposure to other people's teaching methods (observing teaching) and finding opportunities to teach on a small scale level initially. I was offered the opportunity to facilitate a programme throughout the hospital on a monthly basis called "Sage and Thyme". This was a level one communications training adapted from cancer research which the trust was keen to roll out across the hospital, available to staff of all levels. I co-facilitated these programmes over the time that I worked at the hospital. Later in my fourth and fifth years of the doctorate I was also provided the opportunity to work as an associate lecturer, providing teaching to third year undergraduate psychology students in predominantly counselling psychology but also Applied and Health Psychology. By this point I had carried out several teachings within the hospital and with MSc Health Psychology students, this helped to build my experience and develop my confidence further in teaching and training (see appendix teaching log).

Developing my knowledge and confidence to complete a systematic review took longer to accumulate. The university workshop provided some introduction for systematic review. I later sought out training at the hospital library in systematic reviews. I continued to lack confidence and was unable to begin work on my systematic review, which prompted my academic supervisor to again advise me to seek one to one support from the university librarian. I spoke to the librarian specifically about search methods to help me to refine my search terms for my systematic review proposal. Several supervision sessions with my

academic supervisor, feedback and revision of the systematic review proposal helped me to develop a better understanding of what to do and the thought processes involved in completing a systematic review.

### **Unit 1.3 Provide psychological advice and guidance to others**

As part of the Clinical Health Psychology team, our roles were integrated into the multidisciplinary team. This was helpful for advocating the importance of psychology within physical health. We were active in increasing our roles in auditing and monitoring patient outcomes for the transplant and nurse led teams. Small scale research projects such as audit and service evaluation projects were presented to the wider multidisciplinary team at weekly academic meetings that were held for the departmental staff. In these sessions I was able to disseminate the results of the audits to the wider team as well as providing education, recommendations and advice for the way forward, including psychological components to the service that may further improve the service outcomes. Within these academic meetings I was able to present feedback from a regular audit carried out amongst kidney transplant recipients and amongst donors, highlighting their experiences of being transplanted or donating. I was also able to propose to the wider medical team the importance of psychological input at an early stage using interventions such as the "mind and body matters" project and keep the team regularly update on its development.

On an individual level I developed my relationships with the clinical specialist nurses who were often confronted with challenging behaviours with certain patients. Using opportunities such as joining their weekly team meetings I was able to make myself readily available for advice on psychological matters. I was aware of my limitations and for more complex cases I would receive the support from my clinical supervisor. Similarly the transplant and low clearance clinics provided several opportunities for medical clinicians to request for psychological support and advice. Assessments within these clinics would be fed back via

written report. As my experience developed whilst running these clinics independently, medical staff would approach me directly and invite me to case meetings for psychological opinion. I used clinical supervision, research and literature review skills to support the advice I provided to clinicians and relied on feedback from my clinical supervisor and verbal feedback from medical staff to monitor the usefulness of the advice provided.

On a clinical level psychological advice to patients or psychoeducation groups were measured using self-report questionnaires (such as those used when evaluating "mind and body matters") and patient satisfaction questionnaires used by the psychology service.

Verbal feedback was encouraging and helped me to gain confidence that well researched and evidence based psychological advice that I could provide was being taken on board. Much of the provision of psychological advice was also down to developing good relationships with the multidisciplinary teams I was working with. It took time for the medical teams to become more familiar with the work I was able to provide, however it was helpful that the clinical health psychology team was more embedded into the physical health teams. It was noticeably more challenging to develop rapport and provide psychological advice within the inpatient ward setting, however when patients were referred to the psychology service, this provided opportune moments to feedback psychological advice for managing distressed patients. Some health care professionals were more receptive to this than others. Additionally, once a week I would try to attend the ward rounds, to ensure that a psychology presence was felt on the ward for better integration and that ward members of staff would feel more comfortable approaching psychology for one to one advice. This had an impact on increased referrals and health care professionals on the ward requesting for psychological advice for inpatients. Similarly I was allocated clinics on dialysis satellite sites. The relationships built with specialist nurses and other staff on the wards led to the development of the project looking at support for self-care haemodialysis. The recommendations generated

from the project were presented within the dialysis service development meetings with the potential to be taken forward.

### **Unit 1.4 Provide feedback to clients**

Working one to one with patients provided me with many opportunities to provide feedback to clients. Using primarily a cognitive behavioural approach it was important for me to use feedback to the client appropriately. The Cognitive Therapy Scale-Revised (CTS-R) (Blackburn, James, Milne & Reichelt 2001) states that:

"The patient's and therapist's understanding of key issues should be helped through the use of two-way feedback: the two major forms of feeding back information are through general summary and chunking of important units of information. The use of appropriate feedback helps both the therapist to understand the patient's situation, and the patient to synthesise material enabling him/her to gain major insight and make therapeutic shifts. It also helps to keep the patient focused."

Thus feedback to the patient was particularly important as part of the therapeutic process in the form of verbally summarising back to the patient to clarify understanding and validating the patients feelings, feedback of important learning from the session and highlighting unhelpful thoughts and core beliefs. It was important during sessions for me to be constantly aware of the patients' needs and evaluating what feedback was important for the particular problem being presented. Feedback was mainly provided to the patient verbally and often I would support this through written reports or letters to ensure that if further learning was arranged for the next session that the information was also in writing.

Regarding other types of feedback such as feeding back project outcomes to clients, the form in which feedback was provided was generally agreed upon prior to completion of the project. For "Mind and Body Matters" the multidisciplinary team wanted regular updates



through the academic meetings of how the group was running, and by the end of the project they were interested in the results of the outcome measures. For the self-care haemodialysis project, recommendations were disseminated, again through the academic meetings to the multidisciplinary team but also more specifically to the dialysis service development meetings. Further dissemination of both Mind and Body Matters and Self-Care Haemodialysis resulted in conference presentations and for Self-care Haemodialysis, eventual journal publication.

Having a forum such as the regular academic meeting slot allowed the psychology department to share a wealth of psychological education, advice and recommendations. It was a particularly useful forum to provide the team with feedback from psychological research and projects that were being carried out and also demonstrated our teams' value. Due to the diversity of the audience, including specialist nurses, doctors, surgeons, dietitians, social workers and management level staff, presentations at the academic meetings needed to be carefully tailored to the audience, and with a short time frame. This was sometimes challenging but through keeping in mind which audience the information would be most useful for (e.g. Nurses or doctors, dialysis staff or dietitians) I was able to adjust the presentations accordingly. Again, building good rapport with the wider multidisciplinary team helped build interest for psychological projects presented at the meetings.

## **Reflection**

My position as an Assistant Clinical Health Psychologist in End Stage Kidney Disease and Liver Transplant has been crucial experience for my development towards becoming a Health psychologist. There has been a wide range of experiences and opportunities available to me to aid my development and feed my interests. Upon initially beginning my placement and starting the doctorate I felt I lacked a lot of confidence and may have even 'over-compensated' for my lack of knowledge by attempting to 'know' or take on too much. As my doctorate journey has developed acceptance of "not knowing" has been a key skill I have

learnt and further enabled me to grow and learn further. This has contributed to me becoming a better psychologist.

Clinical and academic supervision has also been imperative in my learning to become a health psychologist. Not only has my supervision provided me with reassurance and guidance when I required it but also challenged me to understand more and reflect upon my professionalism. I have also found learning from the multidisciplinary team very useful for my personal growth as a health psychologist.

Having met other Clinical health Psychologists working in chronic conditions, I find it interesting how their locality and whether the psychology team is embedded in the larger physical health department affects their working. I have gained a lot from the closeness of the Renal Team, without their collaboration I would not have been able to complete many of my competencies for the doctorate.

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## **CORE UNIT 3 CONSULTANCY COMPETENCE**

### **Core Unit 3 – Consultancy Case Study**

#### **Background**

For successful management of chronic illness it is widely recognized that the active behavioural involvement of the patient is key (Holman & Lorig, 2000; Department of Health, 2001). End Stage Renal Disease (ESRD) is a chronic disease in which self-care is particularly important. Patients with ESRD experience symptoms which require intensive dietary management, fluid restrictions and complex medication regimens, all of which require patient active and comprehensive self-management (Curtin, Johnson, Schatell, 2004). Curtin, Mapes, Schatell, Hudson (2005) state that self-management involves both the self-management of health care and of everyday life. This includes patients' engagement in activities that protect and promote health e.g. watching for symptoms and signs of illness, adherence to treatment and management of the effects on functioning, emotions and interpersonal relationships (Gruman and Von Korff, 1996).

#### **Context**

The role of the 'Low Clearance' (LC) clinics in the care of patient's with ESRD in the Royal Free Hospital (RFH) is to provide: monitoring and stabilization of kidney function; management of associated symptoms of complications; anaemia management; promotion of health and wellbeing; planning for renal replacement options (dialysis, transplant and conservative management i.e. choosing palliative care instead of dialysis). The Renal Clinical Health Psychology Service including Consultant Clinical Psychologist, Principle Health Psychologist, Assistant Clinical Psychologist; are embedded in the Renal team in the RFH and similarly work with LC patients. Their role to help improve communication with health care professionals; impart psychological knowledge to aid coping with illness; aid psychological

preparation of patients for renal replacement therapy and support patients to fully adhere to their medical regimen. Emphasis is placed on patients at an early stage to self-manage and adhere to medication, be actively involved in treatment decisions and prevent further deterioration of kidney function through lifestyle changes.

At the RFH a “Patient information forum” is run on a quarterly basis. It provides information to patients at an early stage of CKD, its progression to ESRD and renal replacement therapy options, enforcing the message of self-care and adherence to treatment regimen. The patient information forum under the management of the lead LC Clinical Nurse Specialist (CNS) recently began a process of review.

### **3.1 Assessment of request for consultancy**

Feedback from the old programme had been collated by the home dialysis team, who originally took charge of the patient information forum. These highlighted gaps in the current programme in empowering patients to self-care, adhere and address ongoing difficulties following diagnosis and first entering the specialist kidney service. During the review process discussions were carried out between the Lead LC CNS and each renal service to assess how to improve the programme. This prompted The Assistant Clinical Psychologist to carry out a literature review outlining some of the gaps highlighted (Appendix 1).

The Assistant Clinical Psychologist pitched the initial idea of a psychoeducation programme to the LC nursing team and their Lead CNS. The Lead CNS was keen on the idea and recognized the potential in utilizing the skills of psychologists in addressing the highlighted issues. The project involved an additional workshop for patients to enhance and compliment the patient information forum. An additional workshop would enable areas such as psychological wellbeing, empowerment and self-efficacy to be covered in more depth than if the ideas were included briefly as part of the original programme which included mainly important medical information. Psychoeducation has evolved as a “program with a focus on

the didactically skillful communication of key information within the framework of a cognitive behavioural approach – through this patients and relatives should be empowered to understand and accept the illness and cope with it in a successful manner” (Bauml, Frobose, Kraemer et al, 2006).

Schein (1999) defines the process consultation as “the creation of a relationship that permits the client to perceive, understand and act on the process events that occur in (his/her) internal and external environment in order to improve the situation as defined by the client”. This concept was approached during informal discussions and finally a more formal meeting. The client was represented by the Lead CNS (MD) and the consultant and project lead; the Assistant Clinical Psychologist/Health Psychologist in Training (DW). The consultancy contract detailed the time that would be allocated to the project over the next year and a potential cost to the psychology and LC services (Appendix 2). Task lists were collaboratively drawn up at the end of each meeting this helped to keep the project moving forward and ensure each meeting had an outlook.

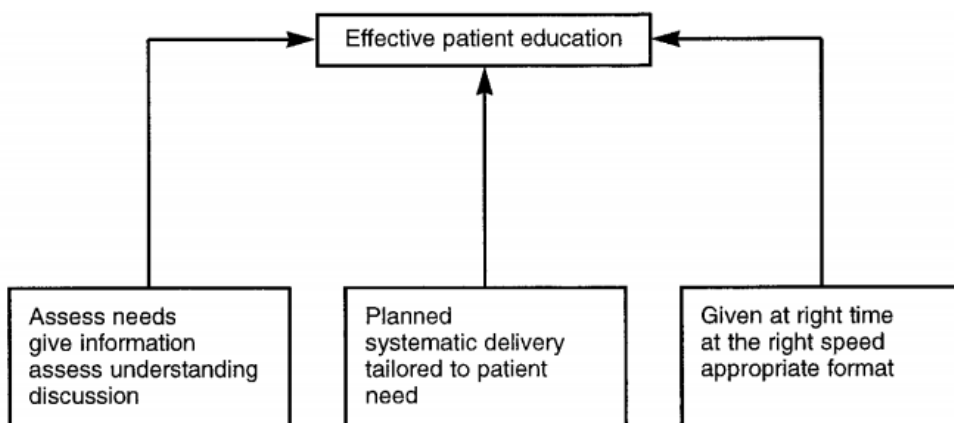
### *Reflection*

Engaging the LC team in an actual project aimed to address the gaps proved challenging. Although the LC team recognised a need for improvement to education provision there may have been avoidance in discussing the issue due to the potential of additional work, cost, time and resources required to address the problems. Informal discussions with key team members played a key role in engaging the interest of the LC team. Through building good communication a process consultation relationship developed between the Assistant Clinical Psychologist/Health Psychologist in Training and the Lead CNS.

## 3.2 Plan consultancy

From the literature review a collaborative decision was made to develop separate educational workshops to support the patient information forums which would focus on physical and psychological factors. The two workshop format was used for several reasons:

1. A lot of information needed to be covered;
2. To reduce attention fatigue (Cimprich, 1992);
3. To be sympathetic to attentional requirements in illness (Hill, 1997; Cimprich, 1992) i.e. to be empathetic to potential symptoms of CKD such as lethargy;
4. To increase potential for shared experiences and supportive interactions to develop over time (Hill, 1997).



Hill (1997)

### 3.2.1 Figure 1 identifies three main components addressed whilst planning the consultancy.

For the first component, 'to assess participant needs and understanding', a pre-session form was completed exploring participants self-reported feelings on how well they understood, coped and adhered to treatment. To ensure that patient education was 'systematically delivered and tailored to participant needs', the sessions themselves followed a structure guided by the presentation. Exploring expectations at the beginning of each session ensured participant needs were covered within the structure. Expectations were reviewed

again within the summary section. Finally, one of the key factors considered was that stage 4-5 CKD patients are likely to attend appointments very regularly, some may have to travel long distances to attend their appointments and many would be under full-time or part-time employment. Symptoms of CKD and ESRD include extreme exhaustion and anaemia. Therefore caution was taken not to add to patient illness burden. Other types of self-management programmes can run over a course of 6-12 weeks (e.g. McGillion et al, 2008; LeFort et al, 1998; Lorig & Holman, 1993). This programme intended to contain all the essential information without running over a lengthy period to adapt the format to suit the cohorts' needs.

O'Donohue & Cummings (2008) specify four components which should be covered in psycho-education including; treatment of the condition; management of the condition; and prevention of progression, exacerbation or relapse. We used this structure to help formulate the programme.

### *Reflection*

Planning the consultancy took a considerable amount of time and research. There was an abundance of information on patient information giving, patient education and self-care; taking components of improving self-efficacy to change health behaviours. Alongside this there was research in psychoeducation with more emphasis on education as a therapeutic intervention within the area of mental health. This project was keen to address psychological and physical self-management in a combined fashion helping patients to feel empowered to understand and accept their illness and cope with it successfully without enforcing a full therapeutic intervention. Coordinating between the psychology team and the LC team what was feasible in regards to limited clinician time and resources was challenging. Adaptations within the programme were made on a regular basis to accommodate these issues. In hindsight I would have picked a simpler project for this competency which required less manpower. However the challenges faced in developing and planning this project provided a

good learning process enabling me to develop project management skills, in addition to learning to apply literature reviews to clinical contexts.

### **3.3 Establish, develop and maintain working relationships with clients**

In many cases a consultancy relationship is managed through an uneven balance of power. This may be demonstrated in other models of consultancy such as the 'providing expert information approach' where the client poses the question and the consultant provides the answer. Or the 'playing doctor' approach, where the client invites the consultant to investigate, 'diagnose' and 'treat' the problem (Schein, 1990; Schein, 1999). A more productive approach used in this context was to find out what would be most helpful at any given moment in the evolving 'helping relationship' i.e. take a 'facilitative' approach (Schein, 1999). This approach allowed the client to be fully involved in the consultancy process, learning and enabling the client to construct their own definitions and understanding of the problem. Thus, empowering the client to use skills learnt for similar problems in the future (Coghlan, 2002). As a consequence the consultation process and the decisions made throughout were less structured and flowed more with the level of trust developed between the consultant and the client (as suggested in principle 6 of the process consultation model by Schein, 1999). Schein states in his fourth principle that "everything you do is an intervention". It was valuable to treat the consultancy relationship as a form of intervention which also required monitoring and evaluation. A close relationship developed between the consultant and the client and this helped in keeping an informal monitoring of the relationship. Records of meetings highlighted that adequate time was spent on ensuring that all concerns were discussed.

#### ***Reflection***

Through initially establishing contact with the client with an assessment of the problem, the client was able to involve herself in the process of diagnosis and so



collaboratively discuss solutions. This was key to ensuring the success of the consultancy. Additionally the client's new role as the lead CNS in LC was to promote and improve self-management for patients. This first engagement and relationship building with the client highlighted Schein's (1999) first principle; "to always have an intention to be helpful to the client, as this will evolve into a mutual learning relationship".

Schein's third principle ("Access your ignorance") drew my attention to the many useful skills psychologists have which can be applied in the medical setting and contracted to provide expert knowledge. I relied on the multidisciplinary medical expertise of colleagues to provide input on the medical treatment and management of CKD in the content of the psycho-education workshops and summary booklets, emphasising the importance of using the full range of skills within the team.

### **Contracts and Budgets**

We negotiated an initial verbal agreement specifying how much time I would allocate to this project (one psychology session a week, £33.45 per session).

### **3.4 Conduct consultancy**

Mind and Body Matters in Renal Care was developed as a 'passive psychoeducational' project. Donker, Griffiths, Cuijpers & Christensen (2009) define this as a method of providing information, education materials and/or feedback/advice. Through our consultancy meetings we agreed that the project would not be intended as part of a patients' routine treatment plan. The project was agreed to be initially piloted as a biopsychosocial educational tool; an option for new LC patients in addition to the patient information forum already offered to service users. At the end of the pilot period the consultancy would be evaluated and deemed completed.

New referrals to LC were identified and sent a letter inviting them to the workshops. This included an information leaflet (Appendix 3) and the forthcoming dates, times and

locations of the next workshop dates. Workshops were split into two half days, and included a presentation (Appendix 4), discussions and activities. An interactive style was emphasized as Lorig et al (1987) deem this a more successful approach for mixed adult ability. Printed summaries were also available during the workshops (Appendix 5).

### *Refection*

Running the psychoeducation groups was a positive experience. The time spent preparing the programme had a large impact on the groups running smoothly and my own confidence in facilitating. Working in conjunction with MD was also rewarding. As a team I felt we worked well and this helped to drive the project forward and prove its success. The greatest challenge was the administrative workload. Alongside my usual one to one patient case load, other teaching/training within the hospital and additional projects I was working on in my role as an Assistant Clinical Psychologist, I lacked time to prepare the paperwork which was required prior to each workshop. In addition to it being time consuming we began to acquire a 'waiting list' for the workshops. We had initially decided upon approximately 15 people per workshop. As workshops would be open for patients to attend with a family member or friend places for workshops began to fill quickly. The waiting list became problematic; we had insufficient time to run workshops every month and although I would allocate those potential participants to the next workshop dates, participants would then drop out. Timing was very much a factor. We wanted to engage patients soon after entering the LC service/diagnosis to approach self-care skills at an early opportunity. However too early didn't provide enough time to adjust from potential shock of diagnosis and too late meant that some patients were at a stage where they wanted to 'get on with life', felt adjusted and no longer felt they required the workshops or had developed 'denial' about their illness. I questioned how I could run the programme without administrative support but additionally how much 'Mind and Body Matters' added to the natural adjustment process that patients' would naturally experience.

### **3.5 Monitor the implementation of consultancy**

Patients were asked to complete a pre and post workshop questionnaire; the first surveying patient knowledge and what they already understand of their renal problems; and the latter surveying whether the workshops met the needs of patients (Appendix 6).

The initial pilot workshops which were carried out ran a format which emphasized medical issues in the first half-day workshop and psychological issues in the second half-day workshop. This was adapted for the latter workshops due to initial findings noting that the 1st session 'adjusting to renal problems' had a higher uptake of participants than the 2nd session 'skills for managing stress and developing coping strategies' which included practical basic coping strategies. However it was also noted that those who attended the 2nd session rated the workshop very highly. This was possibly due to some participants dismissing psychological components as less important than the physical. Informal meetings after each workshop were arranged between DW and MD to monitor the progress of the workshops and whether MD was happy with the format. Initial findings supported the current workshop format with minor improvements. Adaptation of the 1st session included additional information on treatment options and psychological information regarding the impact of stress on health; allowing for more time in the 2nd session to elaborate on sleep and relaxation, pacing strategies and communication skills.

No feedback had initially been collected from relatives or friends who had attended with patients to the workshops. From meetings, it was established that it was equally important to gain feedback from friends and relatives and a 'carer' questionnaire was also created (Appendix 7).

#### **Initial Findings**

The findings can be reported for workshops held over three months. Thirty-five patients opted to attend the workshops, with an additional 25 relatives/friends. Overall, patients believed they had fairly good knowledge on attending both sessions 1 and 2.

However after attending the workshops, participants acknowledged that overall they had learnt more about kidney disease, adherence to treatment, and how stress, anxiety and low mood can have an impact on health. Practical stress management strategies such as sleep management and relaxation were particularly highlighted as useful and participants reported that they would feel more confident in communicating their concerns in medical settings. Participants' motivation and confidence to change lifestyle factors to help improve health was also reported to improve by the end of the workshops.

Verbal and written feedback noted that the overall structure of the workshops were most helpful, allowing patients to attend with relatives or friends. Furthermore, the small groups and open discussion format allowed participants to raise individual concerns, which were shared by the group.

### **3.6 Evaluate the impact of consultancy**

The main goal of the consultancy partnership was to develop a programme involving key psychological components for CKD patients to compliment the patient information forum. Having now completed the pilot which included 4 workshops held over 8 months and achieved the goals set at the beginning of the consultancy, the consultancy contract for this period was ended. A meeting was held to review the consultancy where the following items were examined; what was achieved, the main limitations of the workshops, ongoing concerns (relating to the changing circumstances of our workload as clinicians and the change of focus in the Kidney and Urology Department), the key learning outcomes from the pilot study, and the way forward (refer to Appendix 7 for a more detailed account of the final meeting). Challenges such as general clinician workload, administrative issues and the re-distribution of kidney services to community hospitals proved to be a large strain to the effective running of the workshops. The outcome of the final meeting was to end the running of Mind and Body Matters.

### *Reflection of Consultancy Process:*

I was able to relate well to Schein's experiences of process consultancy. I found that a good collaborative approach with the consultant can be a great advantage when encountering barriers to carrying out a project and enabling a natural 'flow' of progression (Schein, 1999). This consultancy project laid the foundation for future collaborative work with the client as a particularly helpful mutual learning relationship was developed.

There were several barriers encountered throughout the consultancy process including lack of administrative resources and clinician time in particular. Having never carried out a consultancy project of this scale in a small psychology team within the NHS, I underestimated the resources and time that would be required to be allocated to this project. I did not take into account that I would not have any administrative support to help with sending patient invitation letters, pre-workshop preparation and evaluation of pre and post questionnaires. Similarly access was limited for some of the patients located at the Royal Free Hospital satellite sites. This was due to lack of manpower as at least one psychologist was required for the session 1 and at least two psychologists required for session 2. Resources and clinician commitments and availability would need to be evaluated for future consultancies carried out. It would also be useful to consider what alternatives could be used for clinician time.

The pilot study achieved all the intended goals of the consultancy, but was most beneficial in highlighting the main barriers in enhancing self-management support for patients. During the process of conducting the consultancy, a greater drive for self-management in both low clearance patients and haemodialysis patients arose as a high priority area within the department and nationally. This has generated further interest in the project both within the department and from other renal networks. The client and I discussed how components of the project could potentially be used to develop a self-help workbook to aid self-management of renal patients. This idea would address problems of access and help with some of the lack of administrative support within our own department.

Progress and development of the project at each stage was presented at departmental seminars. On a national scale, a further unexpected outcome of the consultancy project was that I was requested to present the project at the European Dialysis and Transplant Nursing Association/European Renal Care Association (EDTNA/ERCA) national conference which I will discuss further in Unit 6. This provided an opportunity to disseminate the pilot to a wider audience.

Through reflecting on the consultancy process and my experience I recognise what is realistic to achieve and what positive outcomes have come out of the project so far. This will be particularly valuable in any further project work I carry out under the role of a consultant.

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## **CORE UNIT 4 TEACHING AND TRAINING COMPETENCE**

### **Core Unit 4 - Teaching and Training**

#### **Lectures in Health Promotion – MSc Health Psychology Programme**

##### **Background**

In the Renal Clinical Health Psychology Team I see patients on a one to one basis and run 'parallel clinics' which run alongside Transplant and Low Clearance outpatient appointments. Clinics provide opportunities for promoting health and maintenance of wellness post-transplant and highlighting healthy behaviours to prevent deterioration in patient who have low level kidney function but do not need dialysis yet. These hands on experiences have provided me with good grounding in practical methods of individual level health promotion.

##### **Context**

Following discussions with my supervisor we agreed that from my experiences and knowledge of using individual level health promotion methods I could provide sessions for the MSc Health Promotion module at City University. In the 1st lecture the aim was to highlight Health Promotion issues in Transplantation giving students an idea of how health promotion is used in an applied setting such as Renal. A later lecture was requested on the general application of individual level interventions in health promotion.



## **4.1 Plan and design training programmes that enable students to learn about psychological knowledge, skills, and practices.**

### **Assess Training Needs**

Training needs were assessed through discussions with the module leader. The learning objectives for the module were then reviewed to ensure teaching was provided at an appropriate level for the students. The 2nd lecture provided an opportunity to ask more questions about what would be expected in an MSc lecture and adapt methods of teaching to suit this to include new theory and practical components to demonstrate application of theory.

### **Literature Review**

The Department of Health ((DH) 2004), National Institute for Health and Clinical Excellence ((NICE) 2004), NICE 2008, NICE 2009a, NICE 2009b have all enforced the importance and need to improve the care of patients with long-term conditions. Each stresses the importance of health promotion and preventative care for patients within long term kidney problems including patients receiving transplants (Frame, 2011). A range of other interventions can also be used to change behaviour: changing attitudes and motivations; increasing physical or interpersonal skills; changing beliefs and perceptions and influencing social norms (Health Development Agency, 2004 (HAD)). Of particular importance, Mental and behavioural health issues in transplantation and the need for psychological assessment (Olbrisch, Benedict, Ashe & Levenson, 2002) to identify factors affecting quality of life and adherence (Frame, 2011). This highlights the importance of health promotion and behaviour change techniques in chronic health conditions. My knowledge, experience and work within this area are therefore particularly useful to demonstrate the application of health promotion techniques to students hoping to work in Health Psychology in the future.

## Identify training programme structures and content

The 1st lecture focused specifically on health promotion applications in transplantation. It concentrated on applying student knowledge of health promotion models to thinking about their uses in 'real settings'. The concept of health promotion in transplantation and further education about the transplant process was used as an example to look at theoretical models and a variety of behaviour change interventions used (see Appendix 1).

The 2nd lecture was more theory orientated. Prior learning from the first lecture provided the opportunity to adapt my style to suit the more 'generic' topic area of 'Individual Level Interventions'. This included up to date aspects of theory and models and aspects of 'real-life' examples from renal care through to smoking cessation, with a mixture of teaching styles e.g. some didactic teaching with some group work.

## *Reflection*

The opportunity to teach on the same module in different years provided time to reflect on teaching styles and how to plan sessions better to suit the learning outcomes and needs of the students. Reflecting on my own learning I considered what teaching styles would be most helpful for the students. Hawk and Shah (2007) suggest that "faculty who are consciously aware of their students' learning styles as well as their own are in a position to make more informed choices in course material, design, and learning processes to broaden the opportunities for effective learning in their courses.... a use of a variety of teaching and learning approaches has the potential to enhance the learning and performance for a wider range of students". With this in mind I tried to think broadly in mixing teaching methods with case study examples, videos and smaller group work to introduce a variety of approaches.

## 4.2 Deliver such training programmes

### Implementing training methods and delivering the programmes

The training methods used were different in each session due partly to the different topic areas. The first was specialised in transplantation; a demonstration of how health promotion can be used in this area. The second was more of an overview of how one would use/develop individual level interventions, using examples from my expert area to make it more applied (Appendix 2). The approach taken in the 1<sup>st</sup> lecture was initially more didactic in style; used to provide information but also trying to engage students through asking questions and using a quiz to gauge student understanding and to encourage students to speak up and ask/answer questions in the lecture. The 2<sup>nd</sup> lecture was structured to break up didactic styles of teaching with smaller group tasks using activities that accommodate Kolbs' (1984) learning process. Concrete experience activities such as video and lecture examples provided clear illustrations of techniques leading to discussion of effectiveness and interventions used (Reflective Observation) and thought questions. Additional reading was provided for students to investigate topics further and opportunities to critique a paper (Abstract Conceptualisation). One area found to be particularly effective was Active Experimentation through the use of case studies (see Appendix 2, Lecture 2).

Concrete Experience	Reflective Observation	Abstract Conceptualization	Active Experimentation
Lecture Examples	Thought Questions	Lecture	Lecture Examples
Problem Sets	Brainstorming	Papers	Laboratories
Readings	Discussions	Analogies	Case Studies
Films	Logs	Text Readings	Homework
Simulations	Personal Journals	Projects	Projects
Laboratories		Model Building	Fieldwork
Observations		Model Critiques	
Field work			

*Source: Kolb (1984); Svinicki and Dixon (1987).*

#### **4.2.1. Table 1: Activities that accommodate Kolb learning processes**

##### **Reflection**

Discussions with my supervisor and watching a recording of the lecture helped me to fully critique and learn from the experience. It enabled me to observe the teaching methods used, looking at what worked and what didn't. The 2nd lecture provided me with the opportunity to apply my learning. For example in the 1<sup>st</sup> lecture Reflective Observation was used well, throughout the lecture students were encouraged to brainstorm and ask questions. However lack of activities within the 1<sup>st</sup> lecture meant that students lacked prospects for progression towards Abstract Conceptualisation and Active Experimentation. Therefore although the session was informative, it had limited opportunity for students to apply their knowledge through processes of 'Self-Regulation and Internal Feedback' (Nicol & Macfarlane-Dick, 2006). The 2<sup>nd</sup> lecture included activities that would enable students to start thinking creatively within health promotion applying learnt techniques.

I have since taken up a post as an Associate Lecturer which in addition to further developing my skills as a lecturer has also shown me how I have improved in my capabilities through experiential learning (Kolb, 2005, 1984).

### **4.3 Plan and implement assessment procedures for such training programmes**

Assessment of student understanding was a continuous process throughout the session. Questions were used to test knowledge along with group tasks to apply learning to case scenarios, discuss problems with peers and question the lecturer individually.

#### ***Reflection***

Informal questioning during group exercises gave me an impression of how well theory was understood. This strategy enhanced opportunities for external feedback to influence student motivation (Dweck, 1999). Dweck also highlighted how external feedback can influence how students feel about themselves and can further guide how students learn. Concentrating on problems in understanding through questioning and small group exercises encouraged students to actively construct their own knowledge and skills (Barr & Tagg; DeCorte, 1996). Thus enabling students to discuss the topic with others and enhance the process of internalising meaning, making connections with what is already known (Lea, Stephenson and Troy, 2003).

### **4.4 Evaluate such training programmes**

After each lecture students completed a feedback questionnaire to assess whether the training programme met their needs (*Appendix 3; Appendix 4*). Evaluation areas looked at whether the lecture met the aims and objectives of the session and module topic area. It also asked for feedback on the lecturer style.

#### ***Reflection***

This experience was useful in progressing my knowledge, skill and confidence in this area. The use of video recordings, feedback forms from students and supervisor discussions were especially helpful. I was grateful that my supervisor spent time watching the recording of my first lecture, observing my second lecture, commenting and critiquing, and highlighting

areas for improvement. She encouraged me to re-watch the recording; in doing so I reflected on my 1st lecture and identified areas of development, this is outlined in more detail in the reflective commentary. A second recorded lecture provided the opportunity to consolidate my learning. I was able to 'transform my learning experience' (Kolb 1984) using valued external feedback in the form of both the students and my supervisor.

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# Teaching Programmes in a Health Care Setting

## Background

My role in the Clinical Health Psychology team includes the provision of teaching and training for other health care professionals. I have done this in a number of ways which include providing foundation level communication skills within the hospital (“SAGE & THYME”) and various informal teaching sessions with Clinical Nurse Specialists and Junior Doctors working in the Renal Service. Since working as a Primary Care Mental Health Worker in 2005 several opportunities have been available to me to train in Motivational Interviewing (MI) including attendance of a number of MI skills workshops and further MI training on the Camden NHS Health Care programme. Building on this, a session was developed as an introduction to MI for Clinical Nurse Specialists.

## Context

Earlier in 2012 a workshop was carried out on the use of MI in Renal Services as part of Continued Professional Development (CPD) provided by the Renal Specialist Interest Group (SIG). Their target group for training basic skills was to Renal Dietitians. In attending the Low Clearance multidisciplinary team (MDT) meetings, nurses expressed an interest in how they could influence their patients’ motivation to change their behaviour (e.g. dietary habits, adherence and lifestyle management) better. They felt frustrated with the lack of influence they had on behaviour change despite their efforts to reinforce risk related information.

## **4.1 Plan and design training programmes that enable students to learn about psychological knowledge, skills, and practices.**

### **Assess Training Needs**

Regular attendance of the MDT highlighted a need for clinicians to take a different approach to communicating and encouraging behaviour change. Nurses would often discuss difficulties faced with patients when communicating risks to prompt patients to adopt healthier behaviours. Discussions with the Consultant Clinical Psychologist suggested that some training could be offered to the team introducing basic skills to support them in their endeavours to promote healthier behaviours with patients.

### **Literature Review**

Health risk appraisal is still one of the most commonly used health promotion tools. In accordance to Roger's (1975) Protection Motivation Theory (PMT) fear-arousing communications should significantly affect the selection of behaviours and responses. However, "risk information alone is seldom sufficient to change complex behaviours" (Kreuter & Strecher, 1996). Miller & Rollnick (1991) noticed a pattern of how practitioners attempted to 'encourage, persuade, cajole, counsel or advise' patients to make changes and have since developed techniques aimed at working through ambivalence and resistance to change using MI. These techniques are found to be significantly (10-20%) more effective than no treatment with one-to-one delivery suggested as a better treatment format (Lundahl & Burke, 2009). Martino (2011) describes MI as a useful approach for enhancing patient motivation with Chronic Kidney Disease, encouraging development of innovative ways to train busy health care practitioners.

## **Identify training programme structures and content**

The Lead Clinical Specialist Nurses (CNS) was approached about providing training in MI. Her interest in MI was due to its transferability to renal services and the ability to carry it out in a time-limited consultation. It was agreed that an introductory session would be best focusing the key techniques used in MI application. One hour after an MDT meeting was allocated to introduce the concept of MI. In this timeframe it would be impossible to provide full training adequately. A condensed session was planned to cover the basic 'spirit of MI' (Appendix 1). The idea was to run through basic information and give the participants an awareness of the usefulness of MI in the renal setting. The session was also developed to inspire ideas of further training in MI and/or thinking of clinicians practice with patients in a different way.

The time constraints of the session played a large role in dictating the approaches taken to delivering the session. To get through the content efficiently a more didactic approach was needed, broken up by a variety of teaching tools. Involvement from the nurses was encouraged by encompassing individual experience through regularly asking questions and using the 'Helpful Responses Questionnaire' (Miller, Hedrick & Orlofsky, 1991) to identify reflective listening skills and empathic ability; skills that are the foundations on which MI is built.

Minimal materials were required for the session. The room used in the hospital was equipped with a computer and projector for the presentation slides. Additional hand outs were provided of the slides and additional material (Appendix 2). References of the evidence base of MI were also given should the attendees want to read about further uses of the technique.

## ***Reflection***

Many of the nurses appear keen to have psychological input and further skills in communication and managing challenging patients. I have provided informal ad-hoc sessions

with some of the nursing teams looking at specific challenging behaviour or how to work with individual patients. Organising in-house CPD has been more challenging despite the overall consensus within team meetings that nurses would like to have more training from the psychologists. However due to time restraints, particularly since many nurses and psychologists in the team have been relocated to community sites, this is often the case causing limited staff and time required to take out for CPD. Although all health care professionals are required to keep CPD up to date, areas such as communication skills training and behaviour change management are rarely mandatory, prioritising CPD for physiological management. What I learnt was most useful in encouraging training to be organised was attending MDT's and ensuring psychology had a strong presence and purpose in meetings. Building good relationships within teams and ensuring that at opportune moments training issues were raised with lead clinicians helped when coordinating in-house training.

## **4.2 Deliver such training programmes**

### **Implement training methods**

Attendees included Low Clearance nurses, specialist transplant nurses and administrators who felt that the training may be useful for when they spoke to patients over the telephone. One of the main challenges was engaging specialist nurses. Often a more traditional 'paternalistic approach' is taken with a patient rather than more 'collaborative styles' of working. This is due to a relatively recent shift from the traditional paternalistic approach to a participatory approach to care (Sidani, 2003). The session provided opportunities for challenging cases such as those faced by the more 'paternalistic' individuals to be used as examples to strengthen the applicability of the teaching session and engage clinicians. If more time had been available those cases could have been developed into role play case scenarios but for the purpose of the time limited training, new perspectives and

ideas of working hoped to help engage interest with nurses using 'paternalistic' models without success.

Practitioners were encouraged to attend the session however the training was not mandatory. The short 1 hour session was intended to optimise accessibility. Despite some non-attendance, those who attended appeared enthusiastic and eager to learn more of MI approaches. In implementing the session all attendees were able to input their own experiences and provide useful contributions. Their input and examples of problems they had faced with patients allowed the session to be put into context and attendees were able to root their learning in real life scenarios.

Effective use of time was required to facilitate the session using other sources of information to refer to for more in depth understanding. The session also encouraged clinicians to seek further training if they were interested and to use the session purely as a 'whistle stop' introduction to MI approaches.

### *Reflection*

If provided a longer time slot, I could have focused more on the use of practical skills and application of MI in Renal. However having lengthier time slots for communication training in general is rare so I made the most of the time that was allocated. In comparison to other trust wide communication training (i.e. SAGE & THYME) we are provided 3.5 hours to complete the training. Each time we are able to fill the entire time slot and are often held back by participants following the session with further questions. Despite my initial feeling that I would not be able to cover enough in a 1 hour slot, upon reflection I realise I covered a lot of detailed information. I did my best to engage attendees with a variety of different teaching approaches, using their examples of problems faced with patients and short tasks to break up the 'lecturing' part of the session. Overall this format appeared to be received well. In hindsight it is easier to see what else could have been included, for example role plays and

discussions around application. However it is important to also be able to learn to work effectively within the restraints posed and I feel that this session helped me to do this.

### **4.3 Plan and implement assessment procedures for such training programmes**

No formal assessment was carried out to assess clinician knowledge following the session. The application of the tools learnt acted as an informal measure to gauge attendees understanding. Feedback from line managers stated further interest in follow up sessions. In later months nurses who had attended also enrolled themselves onto some additional training for MI for health care professionals this was inspired by the short introductory session that had been carried out.

#### ***Reflection***

A formal assessment to assess learning from the training did not seem appropriate for this training. The session was too short and aimed to only give an overview of an alternative approach to facilitating change in patients. However being part of the team I was able to keep note of progress from the clinicians directly. I was encouraged to hear that the ultimate goal of the session; to promote alternative approaches to helping patients facilitate change, had prompted some of the nurses to enrol in MI training. Some of the nurses were keen to have a better understanding and I was pleased when they informed me how helpful the introductory training had been. Following their additional training one nurse, described a few patients that she had attempted MI with and felt improvement may have come about from her knowledge. Having this feedback was heartening and a more suitable form of monitoring and assessment of skills learnt. Despite the challenges of providing training, small advances like these, demonstrate to me that the training was worthwhile.

#### 4.4 Evaluate such training programmes

The main objective of the teaching session was to introduce a different approach to behaviour change which could be used with patients. This was assessed through both verbal and written feedback. Several individuals commented on how useful and relevant the session was in introducing a different perspective to encourage patients to take up healthier behaviours. A short feedback questionnaire was used to evaluate the content and structure of the session (Appendix 3) along with some written feedback. The session was well received with several individuals requesting for information on future training in MI. Despite the positive outcome of the training both the Lead Clinical Nurse and I were unable to continue in-house MI training due to leaving our positions in the hospital.

#### *Overall Reflection*

My teaching experiences in communications skills has made me consider the lack of emphasis on training available in health care and the minimal importance placed on it. A research report looking at 'Exploring staff attitudes to undertaking advanced communication skills training' (Payne, Turner & O'Brien, 2009) highlighted the differences in attitudes between health professionals. It noted "doctors were more resistant to communication skills training than nurses: they felt more strongly that good communication was not essential...and should not require additional training". Although this particular session was targeted at nurses I am aware that in many different professions, including nurses, there are individuals with similar attitudes. On reflection I do feel that this has affected my confidence in my ability to impart knowledge in teaching sessions. For example, when supported by the overall organisation of the Royal Free (i.e. training sessions for the whole hospital in SAGE & THYME) I felt more confident in my facilitation skills. However when teaching medical professionals particularly junior doctors, I often sensed ambivalence in how useful communication training from psychologists could be. This was often reflected in the lack of participants attending. Despite



this, I grew a level of acceptance of the attitudes participants may have, knowing that a training role could influence a change in perception in others. This has enabled me to cope better along with ensuring I always start sessions highlighting the research base and importance of communication skills working in healthcare. Key skills of listening, respect and communication for me are mandatory for working within the NHS. Lack of effective communication is regularly cited as an important reason for failure of care provision with patients but also between health care professionals (Richie, 1994). A culture change is required to ensure professionals receive communication skills training and fully understand its importance. Developing this teaching session has shown me that by getting involved and encouraging teaching in healthcare, small changes can help improve how clinicians consider communicating with patients. Clinicians may in turn be inspired to use skills to encourage healthy behaviours in patients. Effective training can be developed even within the constraints posed of time, NHS culture and attitudes.

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# **CORE UNIT 5 IMPLEMENT INTERVENTIONS TO CHANGE HEALTH-RELATED BEHAVIOUR**

## **Core Unit 5 – Behaviour Change Case Study**

### **Implement interventions to change health-related behaviour**

#### **Service Background**

The Renal Clinical Health Psychology Service is embedded into the Renal Unit at the Royal Free Hospital. Referrals are received from the Royal Free Hospital Renal Unit and six other dialysis satellite sites. The renal service is split into different departments from which we receive majority of our renal referrals. These include General Nephrology, Low Clearance, Haemodialysis, Peritoneal Dialysis/Home-haemodialysis and Transplantation. Referral criteria (see Appendix 1 & Appendix 2) and an information leaflet about the service is available (see Appendix 3). The service is structured to provide psychological interventions in a 'Stepped Care Approach' (see Appendix 4), as recommended by the National Institute for Clinical Excellence (NICE, 2009) discussed later.

My role as The Assistant Clinical Psychologists' at the Royal Free Hospital renal unit requires the provision of brief psychological interventions for patients with mild to moderate mental health and behavioural difficulties triggered by their physical health condition. Previous training in low intensity therapies enabled the continued application of my skills within a health setting and also required me to heighten my awareness of my limitations.

#### **Overview of Chronic Kidney Disease**

Chronic Kidney Disease (CKD) is diagnosed when an individual's kidneys are diseased or damaged. It is the persistent and usually progressive reduction in glomerular filtration rate (GFR or estimated glomerular filtration rate, eGFR). There are 5 stages of CKD (see Appendix

5). At stage 4 CKD patients are managed within the Renal Unit at the Royal Free Hospital within the 'Low Clearance Clinic'. Only at 15% -10% eGFR are renal replacement therapy (RRT) options discussed with patients and a diagnosis of End Stage Renal Failure (ESRF) made. There is no cure for ESRF only 3 main types of treatment; transplantation; haemodialysis (HD) and peritoneal dialysis (PD). Kidney transplantation provides the best long term outcome for patients with ESRF however a lack of donors can mean a 3-4 year wait for an organ. HD involves the individuals' blood to be pumped from the body (either via a 'Line' or a 'Fistula') into a mechanical artificial kidney and then returned to the body. This process cleans the blood of waste products through the use of a solution of electrolytes (dialysate). Hospital HD, which is most common, requires the patient to attend a dialysis unit approximately 3 times a week, for 3-4 hours. PD uses dialysate infused into the peritoneal cavity. It uses part of the kidney to filter the blood of waste products. Patients can be trained to perform PD at home, at work or even while on holiday, allowing some degree of independence and control. PD requires a high self-care element to dialysis including working the PD machine at home. A PD catheter needs to be fitted within the abdominal area which can cause patients to become body conscious and lower self-esteem. Generally adjusting to any form of dialysis can be a distressing process causing many psychological difficulties which can be triggered or exacerbated by side effects (e.g. insomnia, weight gain and back aches). Both types of dialysis require the patient to adhere to strict dietary and fluid restrictions and complicated medication and treatment regimens. Psychological factors in ESRD primarily focus on non-adherence with medical treatment, patient emotional distress and psychosocial influences on physical morbidity and mortality Christensen and Ehlers (2002). Depression has a prevalence rate as high as 20% - 25% in ESRD (Kimmel, Cukor, Cohen, Peterson, 2007) with relations between depression, treatment adherence, social support and modulation of the immune system (Cukor, Cohen, Peterson and Kimmel, 2007).

## **5.1.a Assessing the suitability of client for health-related behaviour intervention**

### **Background information to case**

This case study was selected of a renal patient seen on a one to one basis for guided cognitive behavioural therapy (CBT), (Appendix 6). CBT principles were used throughout the sessions with some skills used from Brief Solution Focused Therapy (BSFT, de Shazer et al, 1986) (Appendix 7).

XX was a female patient, aged 61 of African decent referred to the Renal Clinical Health Psychology team from the PD Clinic. The referral letter indicated that this patient had recently started PD cycling overnight and had been experiencing low mood and an inability to adjust to her treatment (see Appendix 8). As a consequence, the patient had a tendency to neglect her dialysis sessions and was deemed by the medical team to be ‘non-adherent’ to medical treatment. The patient was allocated to The Assistant Clinical Psychologist (DW) during the Renal Clinical Health Psychology team meeting to carry out an initial assessment and, if appropriate, a brief therapeutic intervention.

### **Initial Assessment**

In the initial assessment an agenda was set to focus on XX’s psychological needs, build rapport and an understanding of her problems. At the start of the session XX completed an ‘expectations from seeing a psychologist’ questionnaire and a Hospital Anxiety and Depression Scale (HADS) (see Appendix 9). XX attended her appointment immediately after another medical appointment. She appeared reserved, nervous and initially lacked eye contact and at times was tearful in the session. After initial rapport building XX discussed how she had experienced symptoms of panic and anxiety approximately 3 weeks after she had started on dialysis. She described an incident where she felt so panicked that she convinced herself she had an infection and decided to go to an Accident & Emergency department. XX had lost her

appetite and as a consequence was losing weight. She described being unable to be on her own, regularly requesting for her daughter to stay and sleep with her when her husband was working night shifts. XX experienced sleep disruption, reporting sleeping only an hour or two before she woke up and struggled to fall asleep again. Sleeping pills had been prescribed for her to help her at night.

Exploring lifestyle changes indicated that XX had been employed and a sociable person with many friends prior to her illness, now she was on long term sick leave. XX felt unprepared and unable to cope with the changes dialysis brought and reacted by withdrawing from her friends. XX continued to be anxious during the daytime. She often found herself at home staring at the dialysis machine. This would prompt her to cry, worry about the next dialysis session and avoid dialysis altogether. Risk of self-harm and suicidal ideation was carried out in initial assessment. XX experienced some thoughts that life was not worth living but had no suicidal intent or plans.

XX hoped that through seeking psychological support she would be provided the opportunity to express her distress more openly. Furthermore she felt that speaking to a psychologist might alleviate some of her emotional pain through speaking to someone who has some understanding of her illness.

## **Literature Review and Formulation**

Therapeutic methods that would be most useful to help XX cope with her treatment and manage her anxiety and low mood were explored. From discussions with her renal health care team, it was clear that their agenda in referring XX for psychological intervention for low mood was also to improve her adherence to PD and consequently to maintain stability to her health.

From the literature review several factors such as social support; cognitive factors (including self efficacy, locus of control and components of the Health Beliefs Model (HBM)) and personality influences (Christensen and Ehlers, 2002) had a relationship with individual

adherence in ESRD. Karamanidou, Clatworthy, Weinman and Horne (2008) looked at non-adherence to phosphate binding medication in patients with ESRD. Highlighting that non-adherence is normal within patients and that adherence rates vary between patients and within the same individual over time and across treatment. The authors stated that the key factor to address related to the individual's illness representations (Leventhal, Diefenbach, & Leventhal, 1992).

Some studies have investigated the relationship between depression and non-adherence in ESRD (Chilcot et al 2010; Lennie, Frazier, Khalil, 2010; Cukor et al 2009; Cukor, 2007; Cukor and Friedman, 2005). These note that depression is a common psychopathology in patients with ESRD. Chilcot et al (2010) highlight the adverse effect of maladaptive illness representations in ESRD. Cognitive Behavioural Therapy (CBT) is reported to be effective in challenging maladaptive illness representations and as a suitable treatment for depression (Cukor, 2007; Cukor & Friedman, 2005).

There is no specific guidance for the psychological treatment of patients diagnosed with ESRF. NICE Guidance suggests that 'People with established renal failure have access to psychological support' (NICE, Quality Standards for Psychosocial Support in CKD). Furthermore a Cochrane Review of 'Psychosocial Interventions for treating depression in dialysis patients' (Rabindranath, Daly, Butler, Roderick, Wallace, Macleod, 2009) summarised that there were no randomised controlled trials to support any particular type of intervention for the treatment of depression in the chronic dialysis population. This does not indicate that there is no need for psychological intervention within this population. NICE have developed guidelines for 'Depression in Adults with a Chronic Physical Health Problem' (The NICE Guidance on Treatment and Management, 2009). This identifies 'The stepped-care model' as the framework for provision of psychological services in physical health care. The stepped-care model encompasses two features:

1. That treatment should begin with the 'least restrictive' of those currently available but still provide significant benefit (Sobell & Sobell, 2000) i.e. the impact on the patient in terms of personal convenience and cost is limited.
2. The Stepped care approach is 'self-correcting', i.e. the results of treatments and decisions about treatment provision are monitored systematically and changes are made to 'step up' the level of treatment if the intended health gain is not achieved (Bower and Gilbody, 2005).

NICE guidance for 'Depression in Adults with a Chronic Physical Health Problem' further propose the provision of first line 'Low intensity psychological interventions' which include individual guided self-help based on CBT principles.

### **Reflection**

At first I found the literature for CKD overwhelming, having previously worked in Primary Care mental health, the problems presented in renal patients appeared more complex with many complicating medical factors which I felt would naturally cause psychological distress. Although I was adequately trained to provide the intervention, I did not feel confident with my ability to apply my knowledge with CKD patients. I used clinical supervision to gain further insights into the psychological difficulties of patients on dialysis, practice CBT skills, and plan session goals for future sessions with XX. I recognised how clinical supervision could help guide my work with CKD patients.

## **5.1b Identify and negotiate the behaviour change goals of the client**

### **Defining Goals**

Behaviour change goals were discussed after formulation and discussion of cognitive behavioural determinants. XX was acutely distressed and explained her wish for her illness to 'just go away' so she could go back to living a 'normal' life. Although this goal appeared unachievable due to her diagnosis of ESRD, it was unhelpful to dismiss her goal immediately.



Instead, a 'normal life without illness' was explored with XX. This helped initiate challenging of her thoughts about illness and her ability to cope with PD. Drawing on knowledge and experience of Brief Solution Focused Therapy (BSFT, de Shazer et al, 1986), XX was guided to think about specific, measurable, achievable, realistic, and timely (SMART) goals. Aspects of BSFT helped XX to think about what can be achieved in the present to find solutions for her future. The 'Miracle Question' (see Appendix 7) was used to help XX to construct a concrete vision of a preferred future for herself. This technique was also useful in gaining a fuller understanding of what XX meant by a 'normal life' in the absence of illness. Whilst describing her 'miracle day' she also explained to me how she might know when she had achieved her vision of 'normality'. This enabled XX to recognise that despite being unable to change her diagnosis or dialysis, there were aspects that she could change. Communication with friends and family soon became a goal which would subsequently help her develop a good social network to seek support from. XX began to recognise that she could feel more in control and simultaneously stabilise her health condition by gradually increasing her dialysis sessions, with a view to be dialysing every night.

### *Reflection*

I found defining patient goals challenging as XX found it difficult to decide on goals that were 'SMART'. CBT techniques were used but I also found skills from BSFT were helpful with components of therapy such as goal setting. Using the 'Miracle Question' helped me to identify how XX viewed 'normality' and how she would know she had achieved it. I also found it tricky to synchronise the patients' motivation for seeking psychological support (i.e. for emotional support) with the healthcare professionals' motivation for referring XX to psychology (i.e. to improve adherence outcomes). In this case XX was eventually able to recognise some of the benefits to continuing with dialysis.

### 5.1c Assess the cognitive, behavioural and situational determinants of relevant current behaviour

XX had historically struggled to attend her outpatient nurse led clinics appointments (see Appendix 5). She indicated within the assessment that she had prioritised work over her CKD diagnosis as she was asymptomatic at that time. Since starting dialysis, she had begun to experience the burden of her illness and realise its chronicity. XX was terrified she would never be well enough to return to work and could not visualise being able to integrate being on dialysis into her life. She avoided her work colleagues because she was afraid their perception of her would change, she did not want to appear vulnerable. In addition, XX associated increased symptoms with starting dialysis, and therefore questioned the form of treatment. This highlighted some of the core illness and treatment beliefs that were behind her anxieties, low mood and non-adherence to her dialysis.

The initial assessment brought together 5 components of CBT, emphasising the relationship between a trigger (starting dialysis), her emotions (feeling anxious and unprepared), her behaviour (not eating, avoiding friends, avoiding dialysis), physical symptoms of anxiety and panic, and thoughts and worries about the next dialysis session, how she would cope with her dialysis and worrying about how long the process would take. This information provided enough detail to offer some brief psychoeducation in the initial assessment on how her thoughts, physical symptoms, behaviour and emotions influence each other, using examples from her situation. It was agreed she would attend a further 4-6 sessions. This provided time to work on specific goals, and help facilitate a realisation of how unhelpful thoughts can impact her physical wellbeing, and behaviour, resulting in feelings of isolation and an inability to adjust to dialysis.

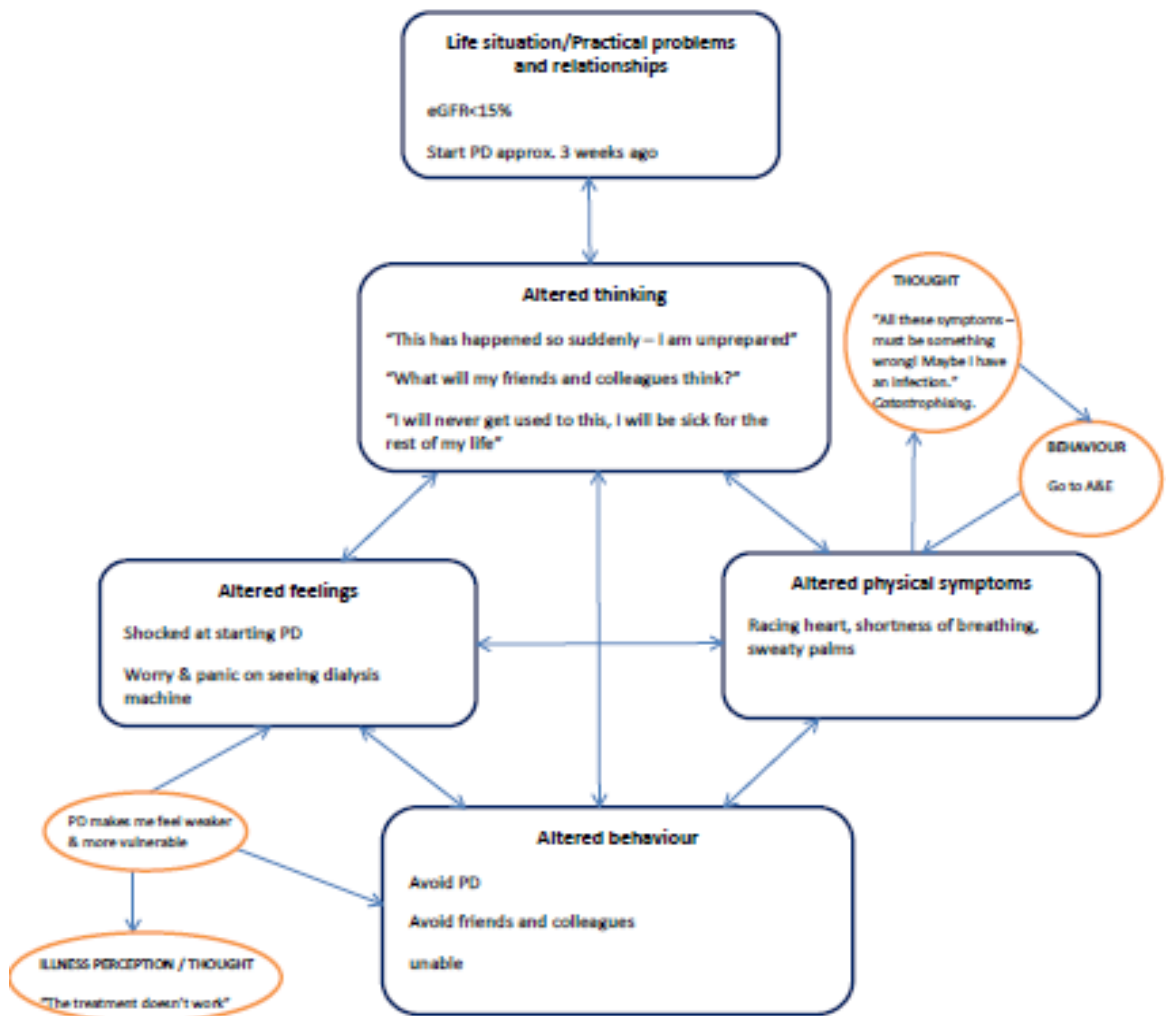
## Session 2 - 4

Focusing on her first experience of feeling panicked when she first started dialysis (which had prompted her decision to go to A&E at a local hospital) enabled her to reflect on the impact of her negative automatic thoughts (NATs) (Figure 1: 'Formulation'). Cognitive, behavioural and situational components were mapped out using The Five Areas Assessment Model by Chris Williams (2001, 2002). Discussing scenarios of non-adherence to treatment allowed DW to prompt for unhelpful thinking styles and health and treatment beliefs which had become barriers. Psychoeducation had already helped XX recognise some of her barriers as she had begun to contact her boss from work and another friend.

XX began to dialyse three or four times weekly. Further sessions were used to discuss NATs and unhelpful thinking styles further particularly related to her disrupted sleep patterns. Thought diaries were also introduced and used as an opportunity to work through NATs and sensitively challenge some of her unhelpful thinking. XX found behavioural interventions such as relaxation techniques particularly helpful, these were practiced within the session and XX was provided with relevant tools to use at home (e.g. Relaxation CD's)

Collaborative discussions helped to review progress. XX had engaged with some techniques, understanding her maintenance cycles and how NATs perpetuated these. In addition to using relaxation techniques XX had been proactive in achieving goals. She made contact with colleagues and friends and discussed going back to work and consequently began to build up her support network and paved a clearer future. XX reported starting to feel more adjusted. There were still some barriers such as worrying thoughts surrounding her future on dialysis and going back to work however XX was managing her NATs better and wanted time to succeed on her own. We agreed to meet for a final session in a couple of months with a view to recapping how to manage continuous unhelpful thoughts, low mood relapse and discharge from psychology.

The Five Areas Assessment model (Williams, 2001)



5.1.c Figure 1: Formulation

5.1d Develop a behaviour change plan based on cognitive-behavioural principles

Each session began with setting an agenda and a recap of the past week events, goal setting and psychoeducation of the CBT model. Barriers to attendance and motivation were identified. Motivation was assessed in session through routine questions like: “How motivated do you feel in making changes to your current lifestyle to help you adjust to dialysis?” XX

appeared to be fairly motivated to change but she felt uncertain that she could confidently adjust to dialysis.

The PD machine alarms prevented XX from falling asleep therefore practical skills were required to help her manage her machine from the PD clinicians. Sleep management strategies and relaxation techniques were factored into the behaviour-change plan to support her as well as discussions on feeling empowered to seek help from health care professions.

### ***Reflection***

I brought this case to my clinical supervisor a number of times. Based on my supervision I adapted the treatment plan to be more flexible to suit the patient. I learnt that because of the patient's chronic illness I had to adapt my sessions to allow for changes in the patient's health.

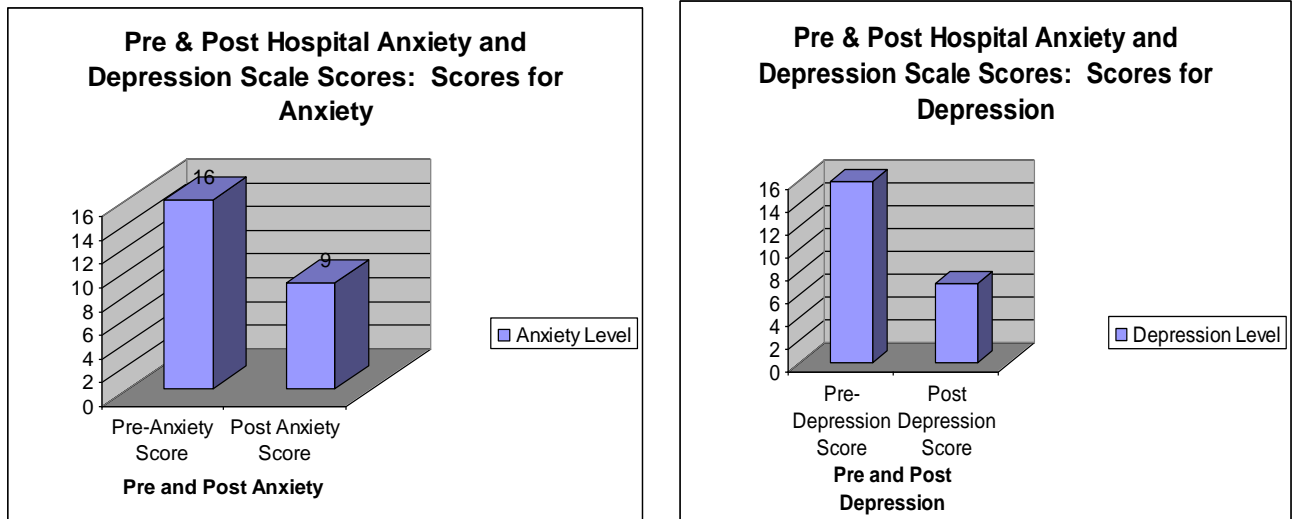
I found differentiating realistic and unrealistic negative automatic thoughts (NAT's) most challenging and attended a day session on 'CBT with older people and chronic illnesses' to support my skills in identifying NAT's. The session looked specifically at exploring automatic thoughts within the context of chronic illness, and developed my understanding and skills in acceptance of uncertainty within the outcome of illness.

### **5.1e Ensure monitoring and support for behaviour change plan**

XX's mood was measured through a subjective method of 'scaling' each session, where she provided a score between 0-10 (where 0 = extremely low mood and 10 = No low mood/very happy) indicating her level of mood in between sessions (Appendix 7). This generated discussions surrounding barriers and days which were particularly 'bad' or particularly 'good'. Adherence to dialysis was also monitored through perception of how she felt she was adjusting and biochemical markers which indicated some improvement. Thought diaries provided good examples of monitoring NAT's and XX's ability to work through scenarios during the session and challenge her own NAT's. This enabled XX to increase

awareness of her own self-monitoring processes, recognising what may have triggered an episode of low mood.

### 5.1f Evaluate outcome



**5.1f Figure 2: HADS Outcome (HADS, Snaith & Zigmond, 1994)**

HADS scores were taken at the beginning of the assessment indicating moderate to severe levels of anxiety and depression. After the fourth session, XX decided to discontinue her appointments. This decision was based upon XX’s feeling that she would be able to continue to self-monitor her mood and challenge her NAT’s on her own. A final HADS was carried out in a closing follow-up session indicating that her anxiety and depression levels had decreased (shown in Figure 2: ‘HADS Outcome’ above). A follow up ‘patient experiences’ questionnaire was completed after the last session indicating that XX’s expectations had been.

### 5.1g Negotiate completion, follow-up or referral as appropriate

In the review session (session 4) it was agreed that outcomes would be communicated with the referring healthcare profession and a plan was made for discharge.

Recently XX was seen as an inpatient and spoken to on the ward. She had received a cadaveric kidney transplant and was recovering from surgery. One of the requirements

of

being eligible for transplant is a good record of adherence to treatment regimen. Since XX had made such good progress with continuing to dialyse regularly in the evening, she became eligible for the transplant waiting list, eventually receiving a transplant.

### *Reflection*

When working with XX, I felt that much of her improvement and coping had been due to a natural adjustment process. However I also felt that XX came away with some useful skills and became much more aware of her emotional wellbeing and its impact on her mood, behaviour and physical health.

I found it useful to discuss each session with my clinical supervisor, who helped me reflect upon my work and develop skills in assisting patients work with realistic and unrealistic NAT's. Finally I felt the whole process helped me to develop skills and a better understanding of adapting basic therapeutic methods to working with renal patients. This case has enabled me to grow with confidence in my continued work with patients with chronic illness.

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## CORE UNIT 6.3 COMMUNICATE PROCESS AND OUTCOMES OF INTERVENTION OR CONSULTANCY

### Core Unit 6 – Case Study

#### Background

“One of the greatest challenges facing health promotion and disease prevention is translating research findings into evidence-based public health and clinical practices that are actively disseminated and widely adopted” (Kerner, Rimer, Emmons, 2005). Durlak, and DuPre (2008) highlight that developing effective interventions is only the first step toward improving the health and wellbeing of the targeted populations. Several steps are required to transfer effective programmes into real world settings and long term maintenance can be difficult and complicated. They suggest that there are four stages that are required for successful diffusion: Dissemination – ‘how well information about a programmes’ existence and value is supplied to communities’; Adoption – Whether the group or organisation attempt to try the programme; Implementation – How the programme is conducted during a trial period and to what standards; Sustainability – Whether the programme is sustained over time. This section will mainly discuss the dissemination phase of implementing the psychoeducation project discussed in *Unit 3 Consultancy “Mind and Body Matters”*.

In a study looking at the experience of disseminating results of doctoral research, Dinham and Scott (2010) highlight that the publication of doctoral results serves the career interest of the students and that publication and/or presentations help students to be able to achieve the professional visibility necessary for the development of academic careers. In the same study Dinham and Scott (2010) found that the most popular means of dissemination for doctoral students was to present at conferences. This was closely followed by journal publications. Other forms of dissemination included writing book chapters, writing books and dissertation abstracts published in newsletters and electronically.

## Context

### **The European Dialysis and Transplant Nurses Association/European Renal Care Association:**

An unexpected outcome of the consultancy project discussed in Unit 3, was a request to present the psychoeducation project as a poster at the European Dialysis and Transplant Nursing Association/European Renal Care Association (EDTNA/ERCA) national conference. The EDTNA/ERCA's was established in 1971 to address the special needs of nurses, social workers, dietitians, technicians, transplant coordinators and unit managers caring for patients with chronic kidney disease and requiring renal replacement therapy. Their mission is to achieve the best standard of treatment and support for patients and families around the world through providing continuing education in renal care. They are a multi-disciplinary renal care organization although tend to attract members primarily from the nursing and medically related professions. In 2011 EDTNA/ERCA held their 41<sup>st</sup> International Conference, with 70 country members around the world including: Australia/New Zealand; Belgium; Germany; Italy; Israel; Lithuania; Poland; Portugal; Serbia; Slovenia; Spain; Sweden; Turkey; United Kingdom.

The opportunity to present at the EDTNA/ERCA UK national conference arose when the lead Clinical Nurse Specialist (CNS), a member of the association, highlighted the theme of 'Psychosocial care' for the up and coming conference. Dissemination and presenting at a conference was not initially discussed or agreed upon in the consultancy contract. Discussions of sending an abstract to the EDTNA/ERCA National conference came after preliminary groups had been run and proven successful and following initial advertising of the psychosocial theme for the conference. The project itself was still evolving and developing, however, after some discussion it was agreed that an abstract could be submitted on the basis that any work presented would be explained as part of 'work in progress'.

Mind and Body Matters was developed in response to a consultancy request to help improve the kidney service education programme (the 'Patient Information Forum'). The aim of Mind and Body Matters was to help newly referred patients, (within the transition period from diagnosis to End Stage Renal Disease) to cope better through general education about their illness and the advantages of enhancing their psychological and physical management. The groups were run as part of a pilot project to address basic medical information relating to end stage kidney disease and dialysis options and additionally highlight psychological wellbeing, empowerment and self-efficacy. Two workshops were developed focusing on "*adjusting to renal problems*" and "*skills for managing stress and developing coping strategies*".

### **6.3a Prepare information for dissemination**

#### **Abstract**

A decision to submit an abstract of 'Mind and Body Matters' for a poster presentation to the EDTNA/ERCA national conference was agreed between the Lead Clinical Nurse Specialist and the Assistant Clinical Psychologist (and project manager for Mind and Body Matters). BMJ Careers (Watson, 2005) highlight that it is important to ask certain questions of projects before submitting conference abstracts. These questions include: "Is your work appropriate to the meeting?" and "Does it fit in with the conference theme?" "Mind and Body Matters" met the criteria for the theme of 'psychosocial care' for the conference. The EDTNA/ERCA however was not an organisation aimed at psychologists, it is targeted at a primarily nursing audience. However, the conference was still considered to be relevant for this project to be presented to because of its multidisciplinary aspect. Clinical nurse specialists within renal are a much larger work force than psychologists and a more influential body within Renal settings. To overcome some of the complexities (such as lack of resources and funding within psychology) it is helpful for Health psychologists to work in partnership with medical specialties within a

multidisciplinary team. Furthermore it is useful to emphasise the work Health Psychologists can achieve within physical health settings that are of a preventative nature and targeting not only psychological wellbeing but also physical and psychological health and wellbeing.

The first step was to develop the abstract to be submitted. Due to the last minute decision to submit an abstract to the conference, less than 3 weeks' notice was provided to put the abstract together to meet the abstract submission deadline date. An abstract template and word minimum of 250 words was set by the conference organisers, other than this, no further guidelines were set for writing an abstract. However, a concise structure including a brief introduction and background of the project and methodology was used for writing the abstract. Brief initial findings from the workshops carried out so far were collated for basic descriptives of the data in the 'findings' section (see Appendix 1: Mind and Body Matters Abstract). Both the lead Clinical Nurse Specialist and the Consultant Clinical Psychologist reviewed the abstract prior to submission as the project was a joint venture with the Renal Clinical Psychology Team and the Low Clearance team.

The abstract was reviewed by a team of 'external abstract markers' who scored the abstracts submitted according to a list of quality criteria. As the conference was a small conference, notification of the results from the review team was quick, taking about 1 month. The abstract was scored highly by the reviewers, who requested that the project be presented as an oral presentation rather than a poster presentation, which the abstract was initially submitted for.

### *Reflection*

One of my concerns at the time of submitting an abstract was that the project had only recently started its pilot. I was wary of presenting work where there was a lack of evaluation data and based purely on a pilot project. Furthermore, as the project and workshops evolved, outcome data collection was also evolving. For example, additional evaluation sheets were developed later for family/carers who had also attended the workshops. Despite my anxieties

I recognized the importance of disseminating knowledge of projects that promote the importance of psychological wellbeing within physical health settings.

An additional initial reluctance to submit the project was due to my own insecurities of having my work peer reviewed. However, discussions with the other team members in the project and clinical supervisors i.e. the Lead Clinical Nurse Specialist and the Clinical Psychologist, helped to encourage me to overcome my fears. The EDTNA/ERCA National conference was likely to be a relatively small conference (approximately 100 people attended) and therefore a 'safe' environment to disseminate the ideas from the project. Dinham and Scott (2010) also investigated the effects of support to publish by doctoral student supervisors. They reported that of those students who reported that they had received encouragement or assistance of some kind from supervisors 77% had published before graduation and 91% since graduating. However, only 44% had reportedly received no support before graduating and 50% since graduating. Furthermore for those students who attended institutions where it was policy to publish, 91% had published before graduation and 100% since graduating. From this experience I realized the value of the support and encouragement from my project colleagues and clinical supervisor which enabled me to push myself to send the abstract for submission and help me to overcome my fears of having my work peer reviewed.

### **6.3b Present information to individuals, groups and organisations on the processes and outcomes of psychological interventions, consultancies**

Approximately one month was given to prepare a presentation for the conference. The oral presentation was allocated 15 minutes in the afternoon slot of the second day of the conference (see Appendix 2: Conference Programme), allowing for questions to be asked at the end. Whilst developing the presentation a background of the project, the psychoeducation sessions and what they involved was put together with basic descriptive results from the

evaluation outcomes measures from the project [See Appendix 3: EDTNA/ERCA Mind and Body Matters in Renal Care Presentation]. The presentation raised a lot of interest from the conference attendees with several questions about how to implement a similar sort of programme on other sites or integrate psychological components into existing renal education programmes

### ***Reflection***

As I had limited experience presenting in a conference setting I arranged for a practice run through within the Low Clearance multidisciplinary team meeting. This allowed me to gain critical feedback and comments from a smaller group of clinicians and adapt my presentation accordingly. In general I received positive feedback and few changes were made to the presentation. The practice run through amongst a much smaller cohort, familiar clinicians and still within a professional environment helped to build my confidence a little prior to the conference presentation.

### **6.3c Evaluate the impact of disseminated information**

No formal evaluation forms were sent out during the conference. However the presentation was evaluated by the response from the conference attendees and verbal feedback received during and after the presentation. Conference delegates asked questions about the set-up of the project, how easy it was to set up and the development of the materials. There were positive comments regarding the idea and its execution. Furthermore at the end of the conference an award was given to the best abstract and presentation from the conference. This was awarded to Mind and Body Matters in Renal Care. The reward received was a bottle of wine and a paid year's subscription to EDTNA/ERCA and the Renal Care journal.

Other outcomes from the presentation and dissemination of the project have been ongoing contact from clinicians from other renal services across the country and even within

South Africa. Clinicians who have been in contact have requested for support and workshop resources developed during the consultancy that may be of use when setting up similar projects in their own localities.

### *Reflection*

The conference presentation, despite my nervousness appeared to go smoothly and with good response from the audience. The abstract submission and conference presentation was a positive and helpful learning experience for me. With the encouragement from the Lead Clinical Nurse Specialist, who also attended the conference with me, I was able to overcome some of my anxieties of being peer reviewed. Additionally, not only specialist kidney and transplant nurses attended, there were also some psychologist attendees. Overall I was pleased with the achievement, however I was most pleased with the ongoing interest in Mind and Body Matters following the conference. The ongoing interest indicated to me that other professionals felt that the idea of integrating psychological wellbeing, empowerment and self-efficacy was a novel and worthwhile idea in developing preventative healthcare. Thus also potentially moving on to the next phase of successful diffusion - 'Adoption' (Durlak, and DuPre, 2008). Aware of the time consumption of work required to set up such projects in other localities 'from scratch' I passed on relevant resources, presentations, research and material to clinicians who had asked about the project and who had interest in setting up similar programmes in their localities. However I requested that any work developed from the resources I had passed on, acknowledge the original developers. Since passing on the materials, however, I have not heard about whether Mind and Body Matters have been further implemented in other localities.



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# **SECTION C: APPENDICES**

# **APPENDICES: CORE UNIT**

## **3**

### **CONSULTANCY**

## Appendix 1: Project Proposal

### Title of Project: Mind and Body Matters in Renal Care

#### Abstract

*Background:* Management of ESRF can place an extreme psychosocial burden upon patients and their families, with many problems occurring during 'transition phases' such as transition onto dialysis. Long term adherence to treatment continues to be particularly difficult in many chronic illnesses including CKD. Communication difficulties and psychosocial problems can have a large impact on patient ability to follow treatment regimens. Incorporating self-management of chronic illness into daily living can help patients feel better informed about their healthcare and more actively involved in making treatment decisions. Understanding of one's medical condition is also a significant predictor of treatment adherence.

*Aim:* To help patients who are in the transition period from diagnosis to ESRD to cope better through general education about their illness and the advantages of enhancing their psychological and physical self-management.

*Method:* New patients entering the Low Clearance service will be identified via database search and sent a letter for them to opt into the 2 workshop programme. Patients opting in can attend one or both sessions with an accompanying friend or family member. Workshops will focus on "Adjusting to Renal Problems" and "Skills for managing stress and developing coping strategies".

*Evaluation:* Workshops will be evaluated using pre and post questionnaires.

#### Introduction

Patient understanding of their medical condition and treatment options is one of the most salient predictors of treatment adherence for many medical conditions (Dunbar-Jacob & Schlenk, 1996; Kastrissios & Blachke, 1997). Patients' who are able to incorporate self-management of their chronic illness effectively in their daily living, feel better informed and more actively involved in making treatment decisions and are therefore more adherent to their treatment (Gerbert et al, 1991). Kok and Schaalma (1998) highlight the importance of distinguishing between adherence and self-management in chronic illness, describing adherence as "blindly following health recommendations" and self-management as "people in their own environments becoming empowered to make good decisions on the basis of physiological and psychological disease symptoms".

Psychoeducation is a model in which education is offered to individuals with psychological disorders and physical illnesses (Donker, Griffiths, Cuijpers & Christensen, 2009). 'Passive psychoeducation', is defined as a method of providing information, education materials and/or feedback/advice. Donker et al (2009) found that brief passive psychoeducational interventions can help reduce symptoms, are easy to implement, can be applied immediately and are not expensive. This project aims to target patients who have low level kidney function and are approaching renal replacement therapy. It will provide an option for helping individuals cope better with

ESRD through education about the nature and treatment of their chronic illness and the advantages of enhancing their psychological and physical self-management. Mitchell et al (2009) highlighted 'preparation', 'cognitive style' and 'social support' as key concepts in supporting patients during transition periods (such as diagnosis and transition to renal replacement therapy) this project will attempt to capitalise on these concepts. A final aim is to introduce and normalise renal psychology services to renal patients, making psychology more prominent and accessible by the patient in the future.

**Main aim of the study:** Pilot study to help patients who are in the transition period from diagnosis to ESRD to cope better through general education about their illness and the advantages of enhancing their psychological and physical self-management.

### **Method**

This pilot project will offer patients entering the Low Clearance Clinic workshops which will cover topics such as basic CKD information, adjusting to diagnosis, adherence to treatment, stress management and communication. Workshops will be run by specialist psychologists and supported by a Low Clearance nurse. The workshops will be held at the Royal Free Hospital and participants have the option to attend session 1 or session 2 or both groups. Participants will be asked to complete pre and post workshop questionnaires about their knowledge.

Target audience: Patients new to Low Clearance Kidney services i.e. patients whom have been in the service for 6 months or less. The service provides nurse led access to specialist renal health care to adults over the age of 18. As long as patients opt in to the programme either by phone or reply slip they will be eligible to attend their requested workshop(s).

Recruitment: Patients will be identified via database search and referrals. Those identified as new to Low Clearance within the last 6 months will be invited to attend two 'psycheducational' workshops via letter. An information leaflet will be enclosed with the letter, and a phone number, reply slip and pre-paid envelope. Participants will be given unlimited time to reply and opt to go to either session 1 or session 2 or both workshops. Groups will be limited to 12-15 people per workshop, and relatives and carers will also be encouraged to attend. In order to assess patients' knowledge and confidence in self-management, participant will be requested to complete a questionnaire before and after the sessions.

Workshops: The workshops will be split into two sessions on two half-days and include a brief presentation, discussions and activities with the intention for the workshops to be mostly interactive approach. Sessions will be run by specialist psychologists. A printed summary will be provided for patients during the workshops. The first session will focus on '*adjusting to renal problems*', including a chance to review patient knowledge of the kidney and renal disease; coming to terms with diagnosis; coping; and issues concerning adherence. The session will be supported by a Low Clearance nurse who provides specialist medical knowledge. The second session will focus on '*skills for managing stress and developing coping strategies*'. It will include issues such as helping patients to identify symptoms of stress, low mood and anxiety; discussing

how stress, anxiety and low mood can affect their health; sleep management strategies and relaxation techniques; empowering self-care and communicating with health care professionals.

Evaluation: The pilot is set out to initially assess patient and carer uptake of the programme, generate patient feedback and benefits for ongoing workshops. An initial questionnaire will be provided to participants prior to the workshops, to assess patient background, prior knowledge, expectations and confidence in self-management. The workshop will be followed by an evaluation/feedback form looking at any change in knowledge, confidence in self-management of their illness, and improvements that could be made to the workshops. Additional written feedback from participants will be recorded

#### References:

Donker, T., Griffiths, K.M., Cuijpers P., Christensen, H., (2009) Psychoeducation for depression, anxiety and psychological distress: a meta-analysis. *BMC Medicine*. 7:9.

Dunbar-Jacob, J., Schlenk, E.A., (1996) Treatment adherence and clinical outcome: Can we make a difference? In Resnick, R.J., (Ed) Rozensky, R.H., (Ed) (1996) *Health Psychology through the life span: Practice and research opportunities*. Washington, DC, US: American Psychological Association. Pp323-343

Gerbert, N., Hummelink, R., Konning, j., Staab, D., Schmidt, S., Szczepanski, R., Runde, B.,  
Wahn, U., (1998) Efficacy of a self-management program for childhood asthma – A prospective controlled study. *Patient Education and Counselling*. 35, 213-220.

Kastrissios, H., & Blachke, T., (1997). Medication compliance as a feature in drug development. *Annual Review of Pharmacology and Toxicology*. 37, 451-475

Kok, G., Schaalma, H., (1998) Theory-based and data-based health education intervention programmes. *Psychol Health*. 13: 747-51

## Appendix 2: Contract and Budget

**Goal:** To develop a programme involving key psychological components for patients to compliment the renal patient information forum.

**Objectives:**

- Support patients in transition period from diagnosis to ESRD.
- Provide general education about their illness.
- Develop patient understanding of psychological and physical self-management.
- Monitor uptake of programme and feasibility of ongoing running of psychoeducation group for patients and carers.

**Consultancy Request:** For the Trainee Health Psychologist to develop a strategy for emphasising self-care and adherence to patients recently diagnosed or first entering the specialist kidney service.

**Time Frame:**

Dates	Tasks
May – September 2011	Stage 1: Dates set for 3 pilot workshops (including 2 sessions each) to be run over a period of 4 months. Stage 2: Monthly monitoring of number of participants and evaluation forms.
July 2011	Mid review meeting with client.
October 2011	Review of pilot workshops.
October – November 2011	Present findings at team meetings and renal academic seminar
December 2011	Complete consultancy

**Budget:**

Agreed time allocated = 1 psychology session per week

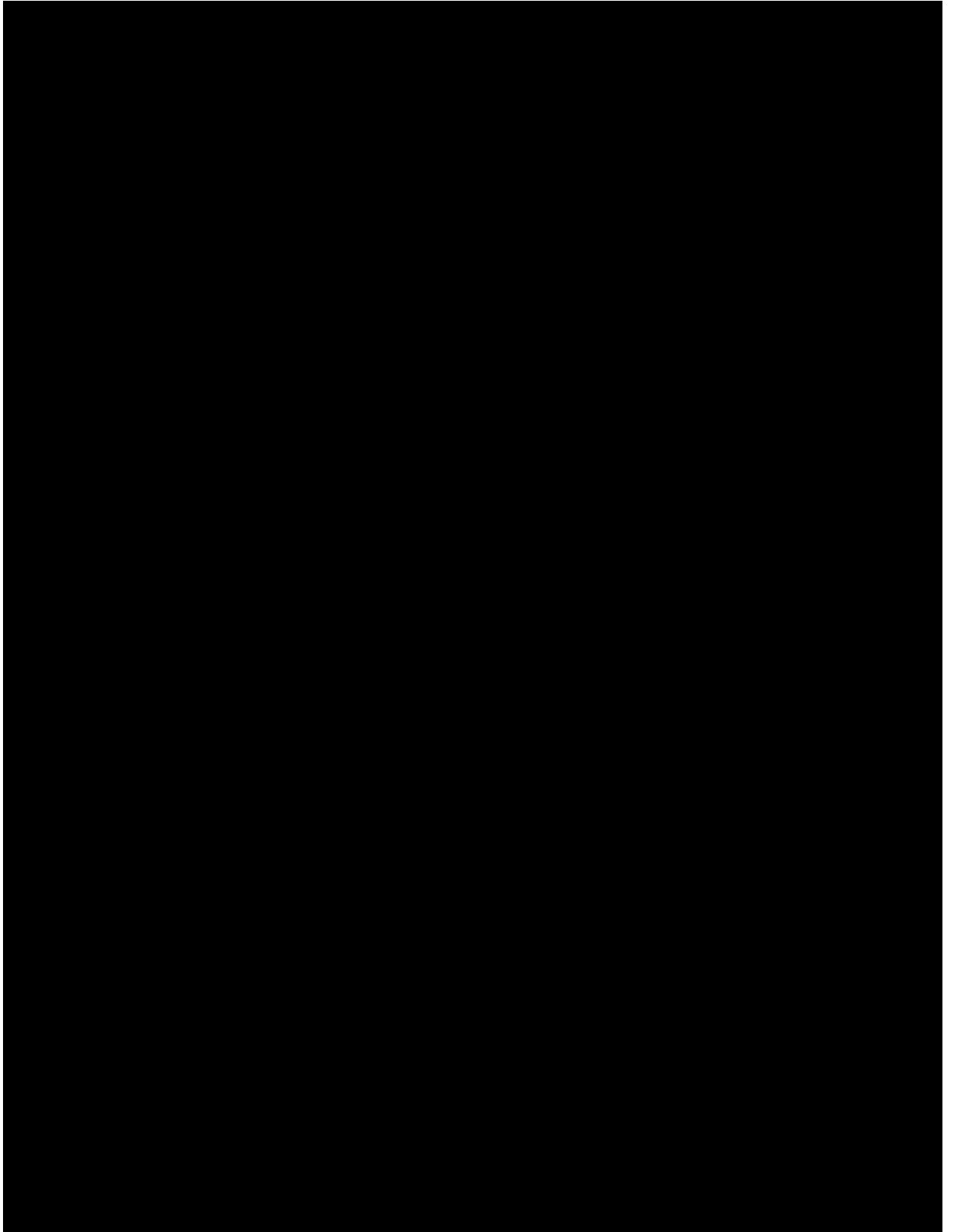
One psychology session = £33.45

Total consultancy period = 32 sessions = £1070.40

Tasks/outcomes agreed within consultation period:

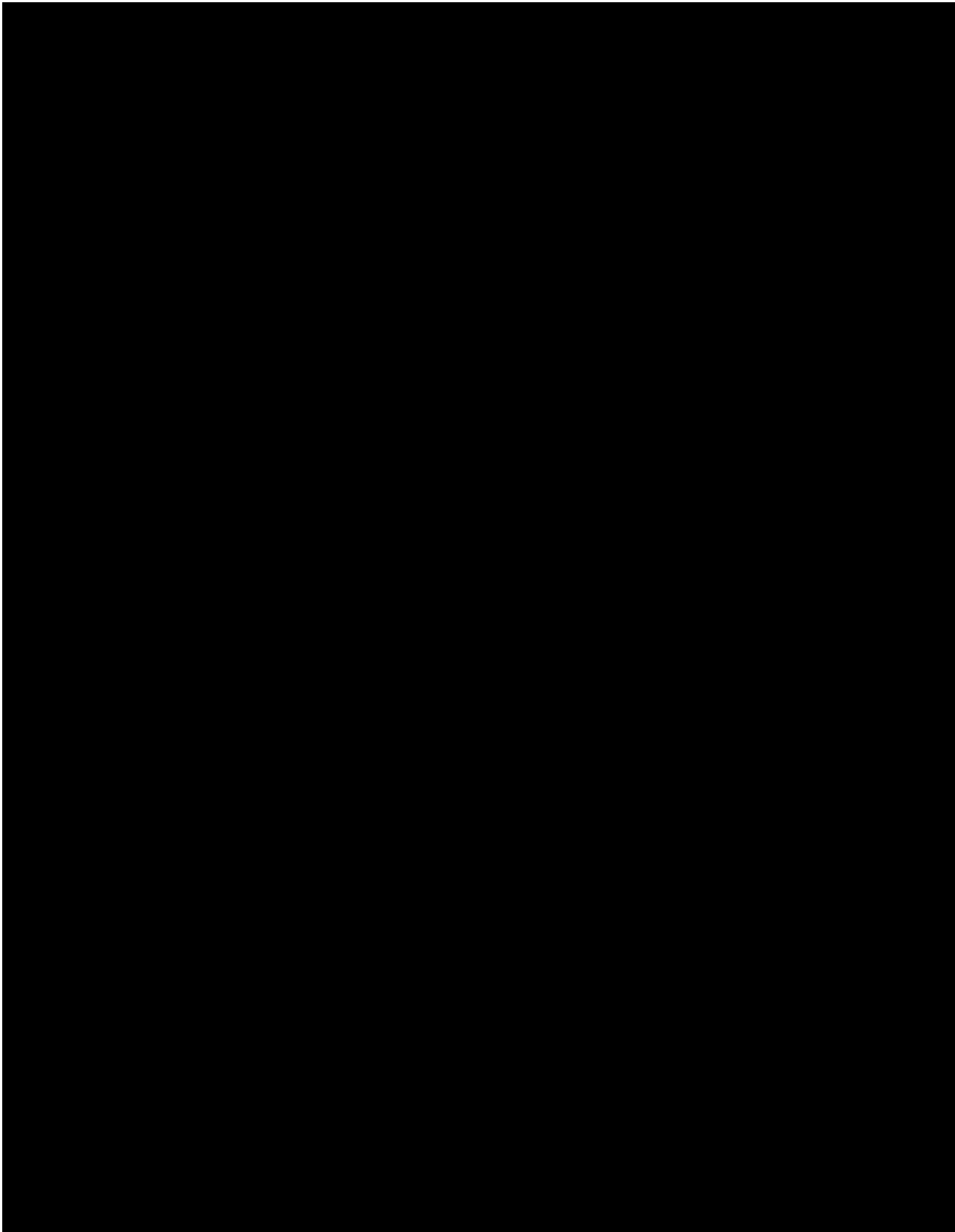
- Development of workshop material i.e. programmes, summary booklets, evaluation forms, presentations.
- Database search.
- Administrative tasks i.e. letters to patients, workshop organisation, refreshments, room bookings.
- Facilitating 2 workshop sessions per month.
- Ad hoc meetings with client including one agreed mid-pilot review and one overall pilot review.
- Monitoring and evaluation of workshops i.e. workshop participation and feedback forms.
- Presentations to renal team meetings and academic seminar.

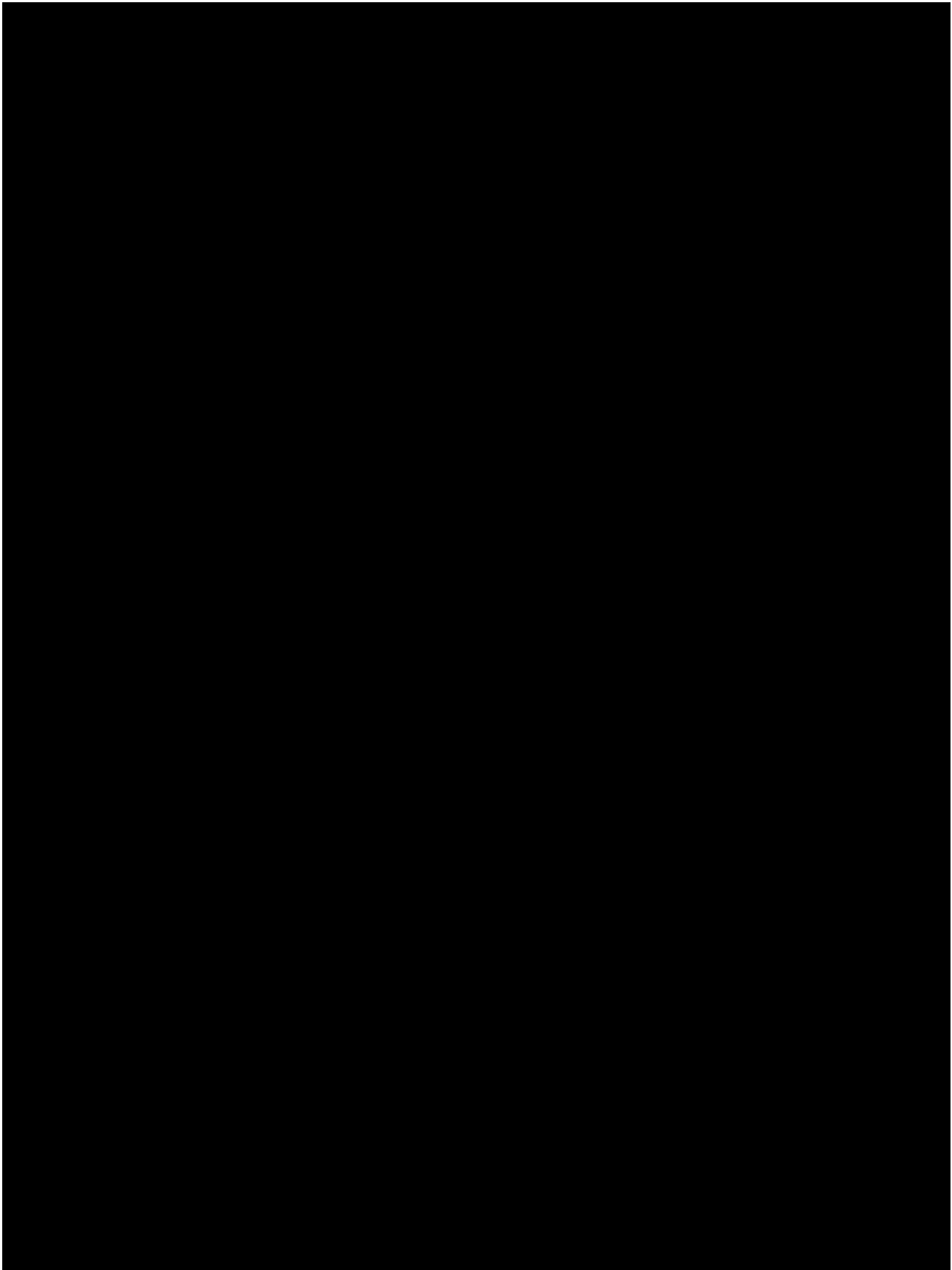
### Appendix 3: Information Leaflet

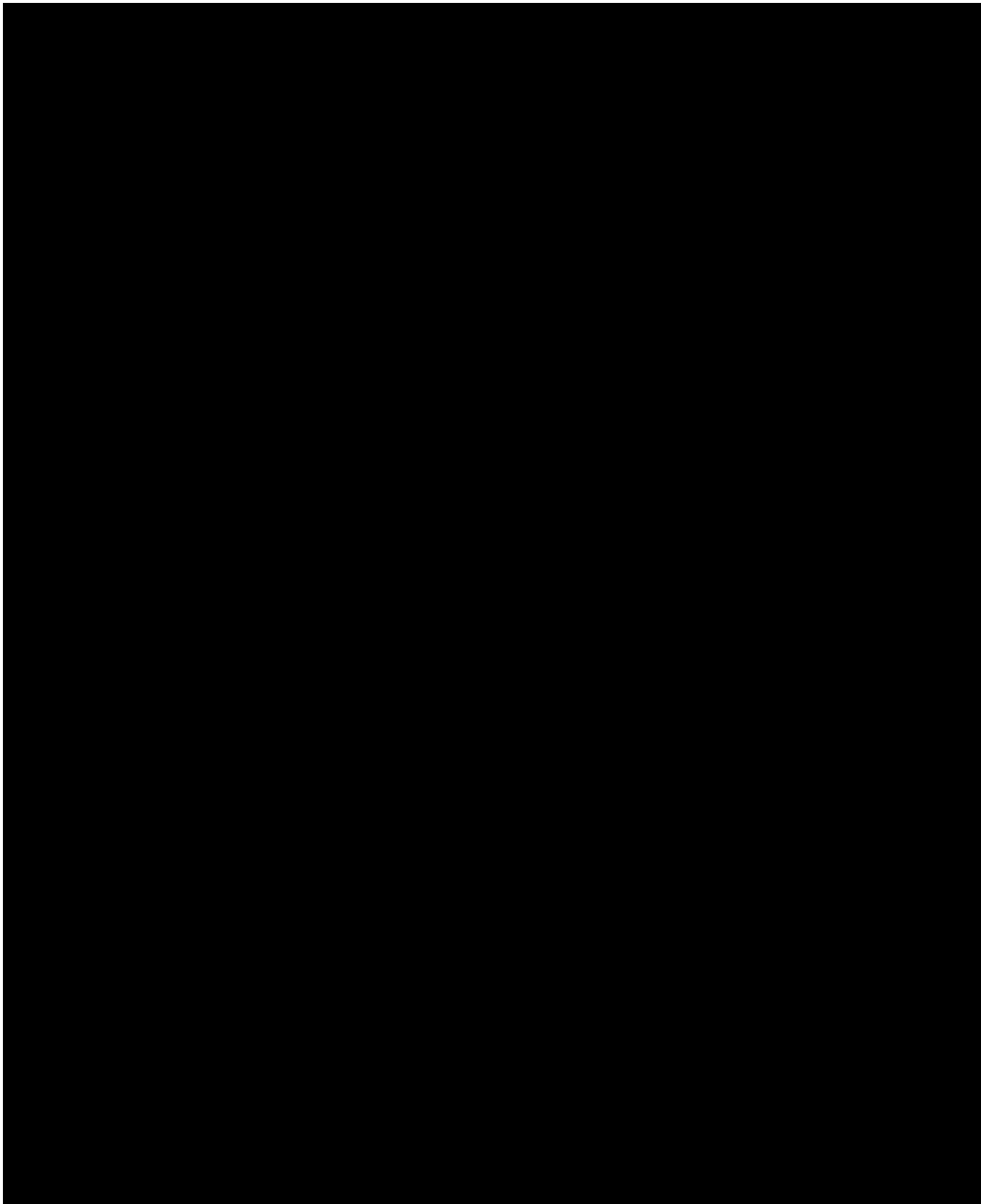


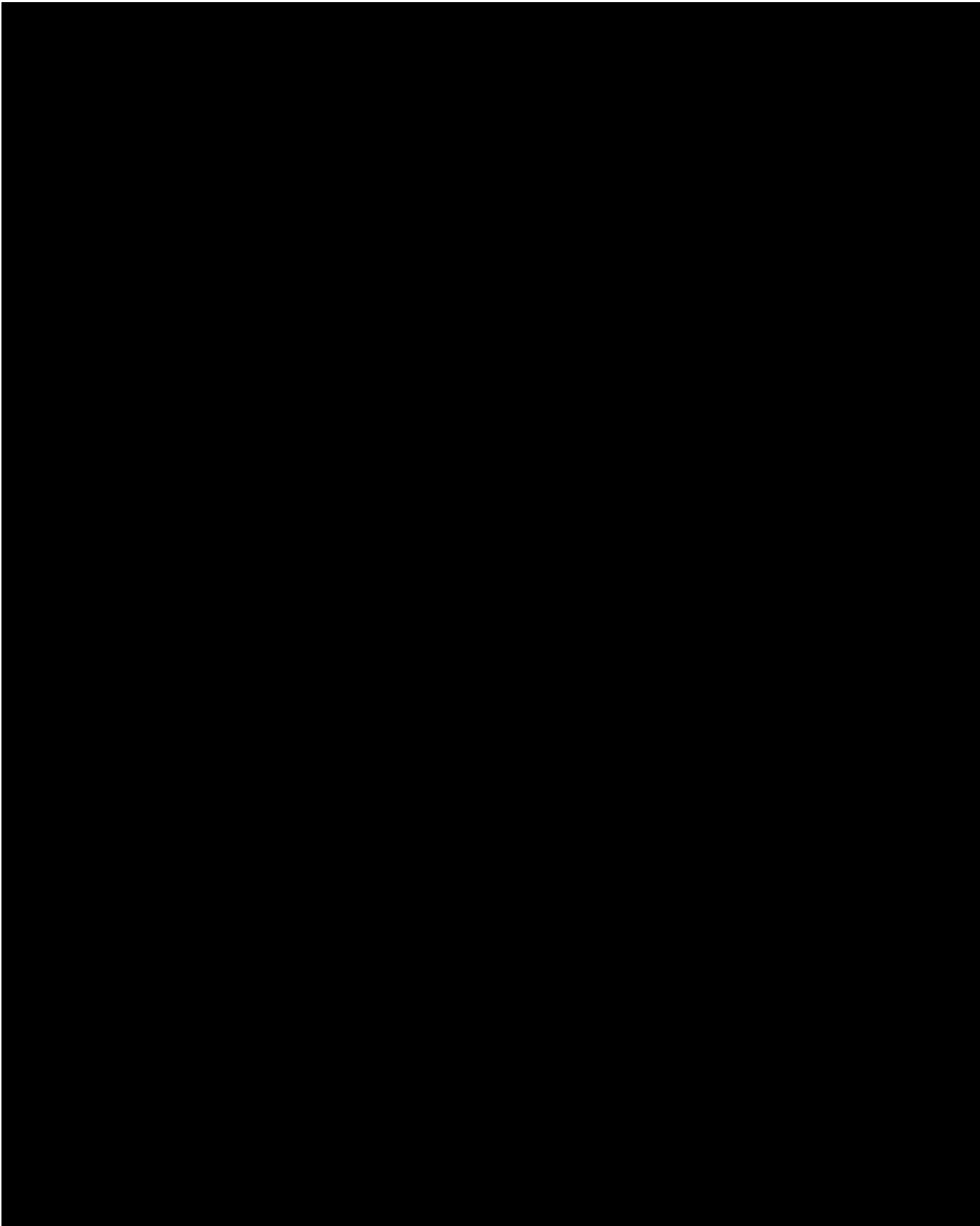


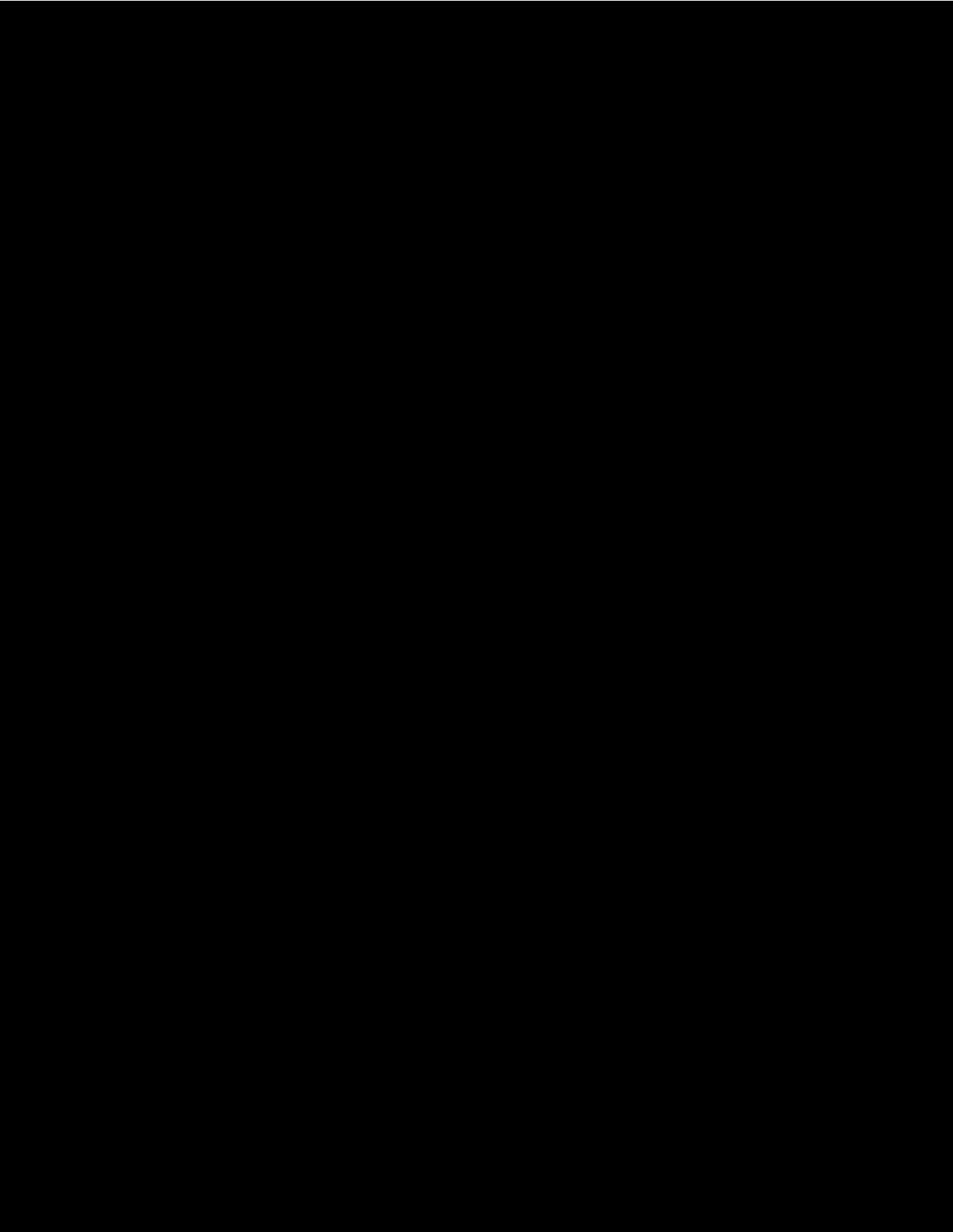
## Appendix 4: Workshop slides - Session 1

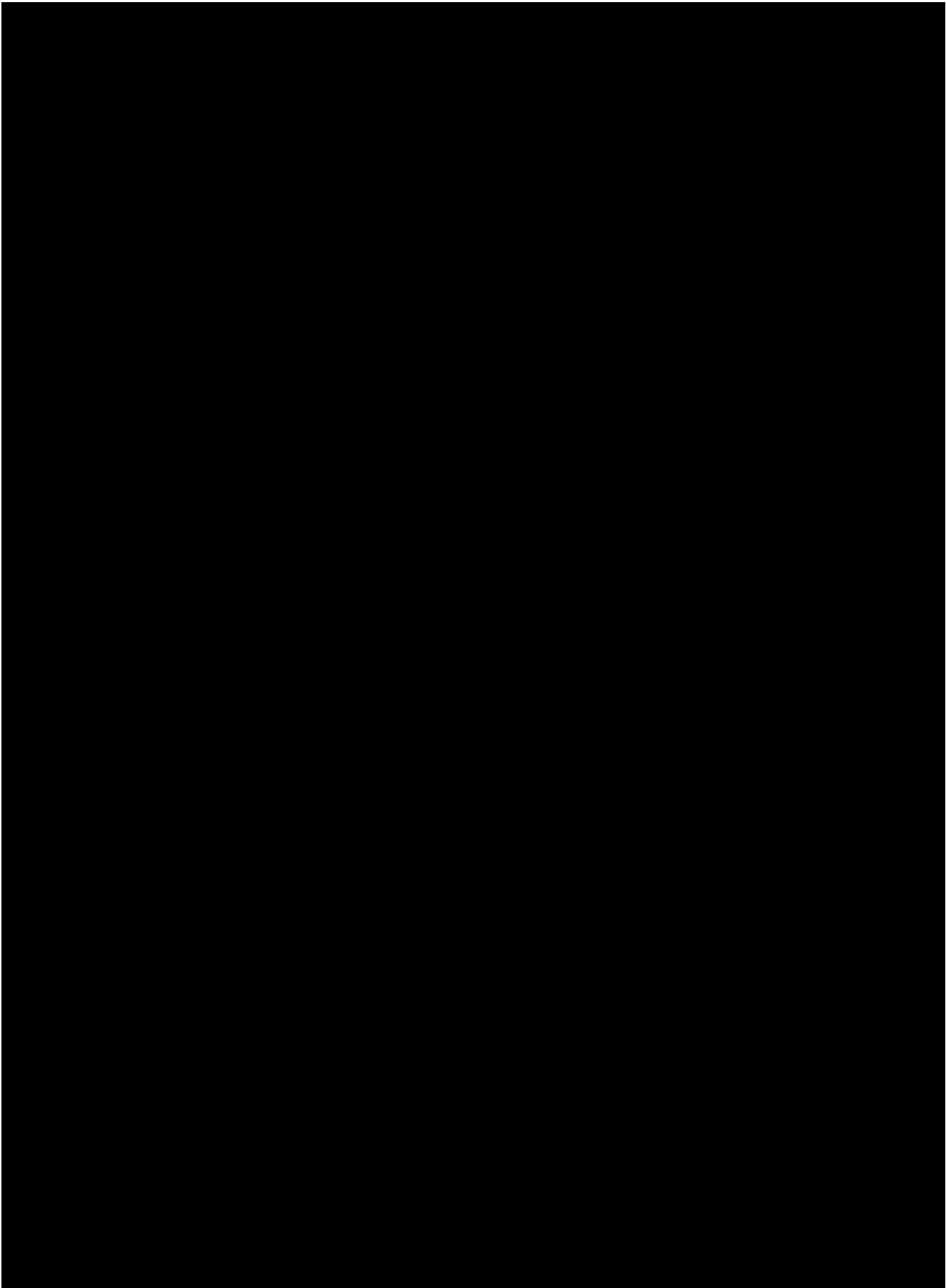




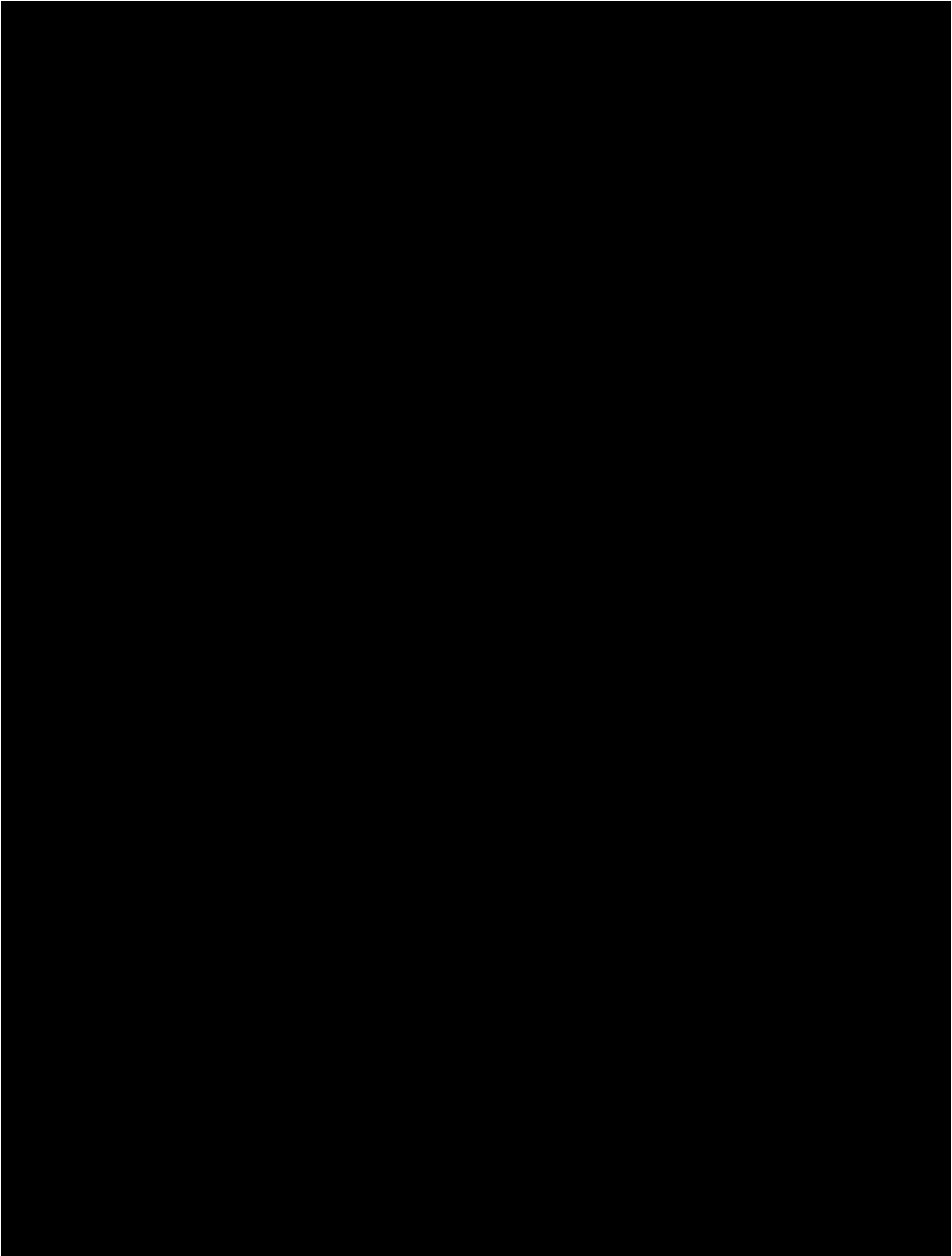


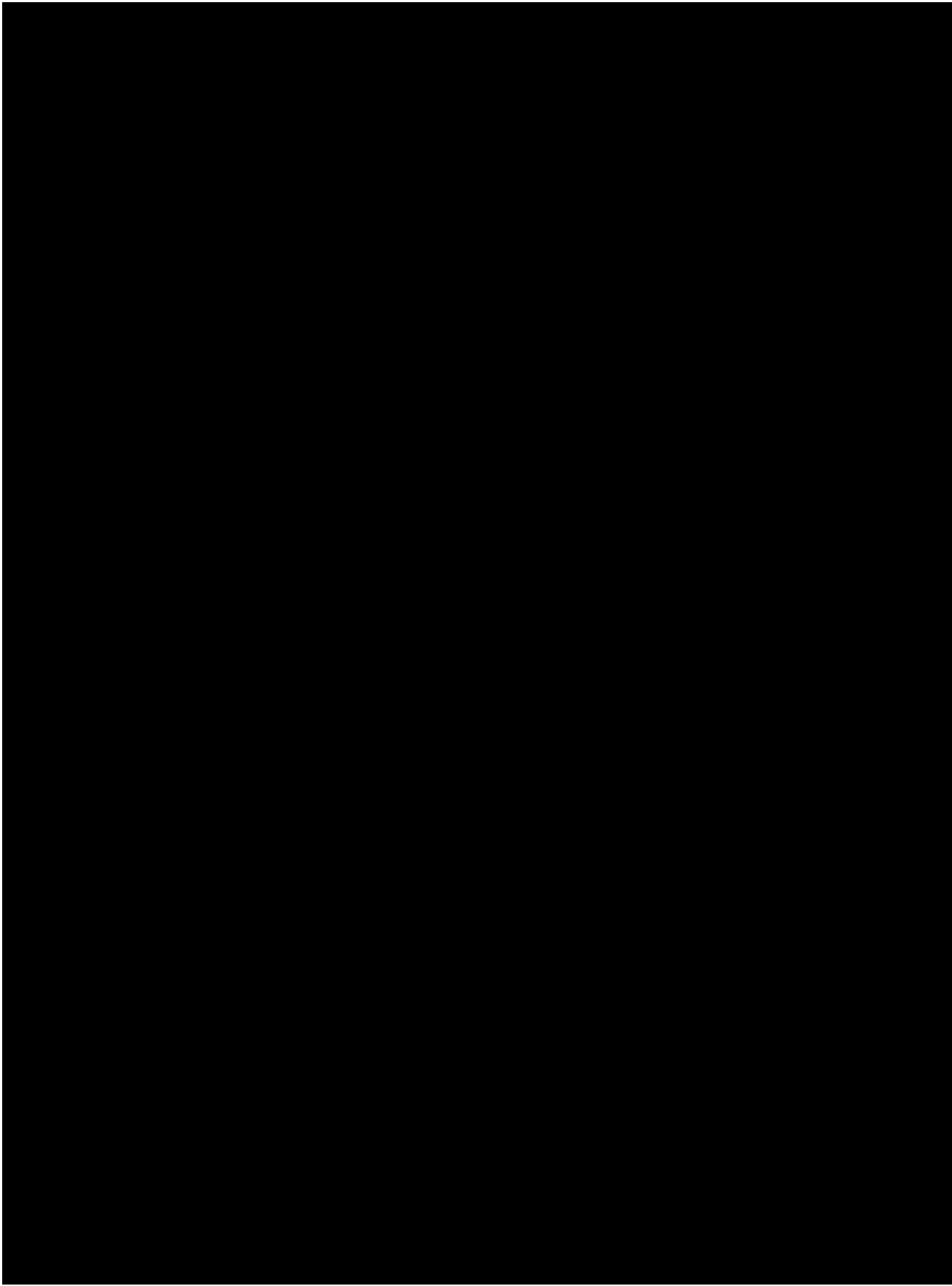




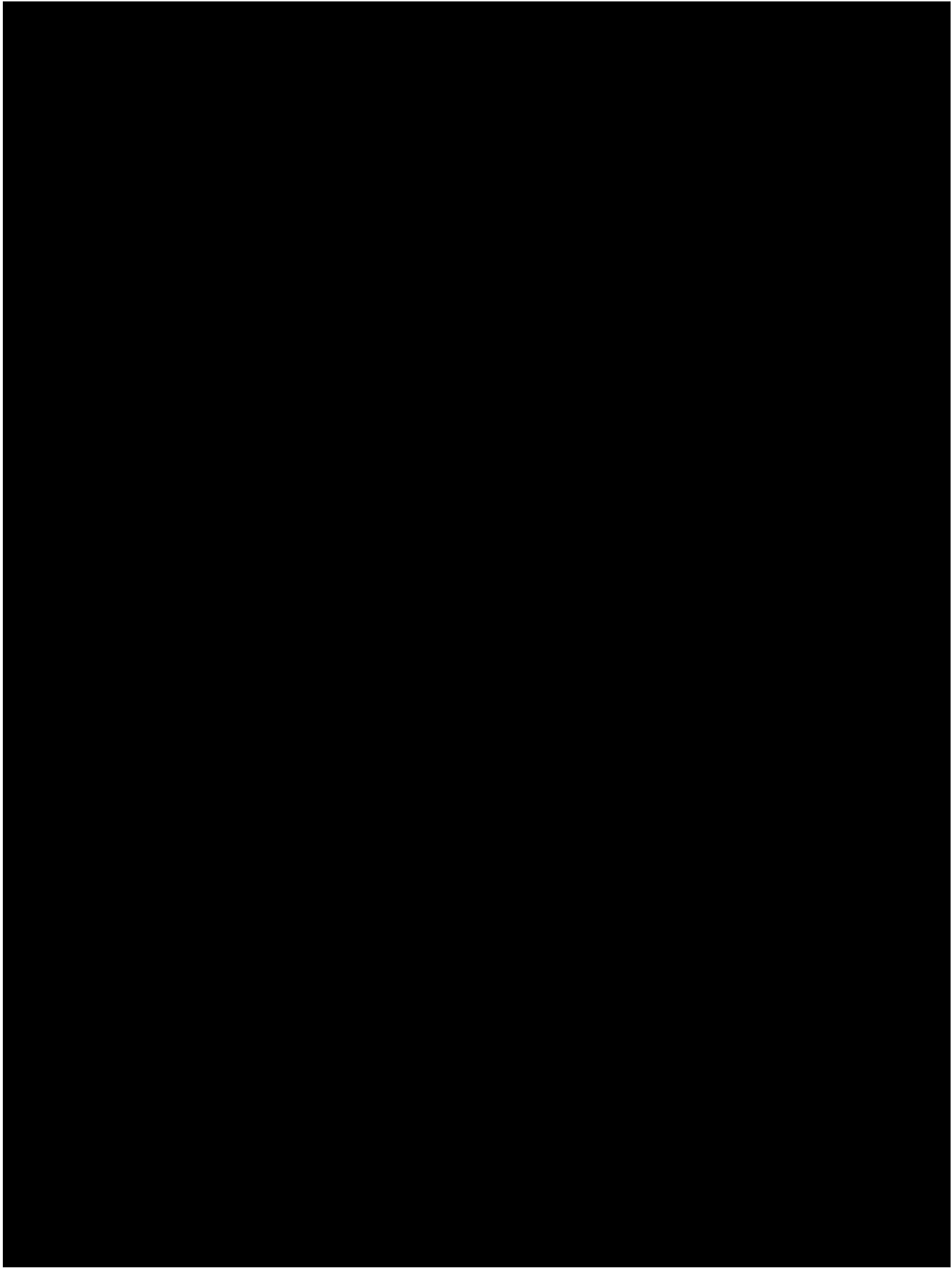


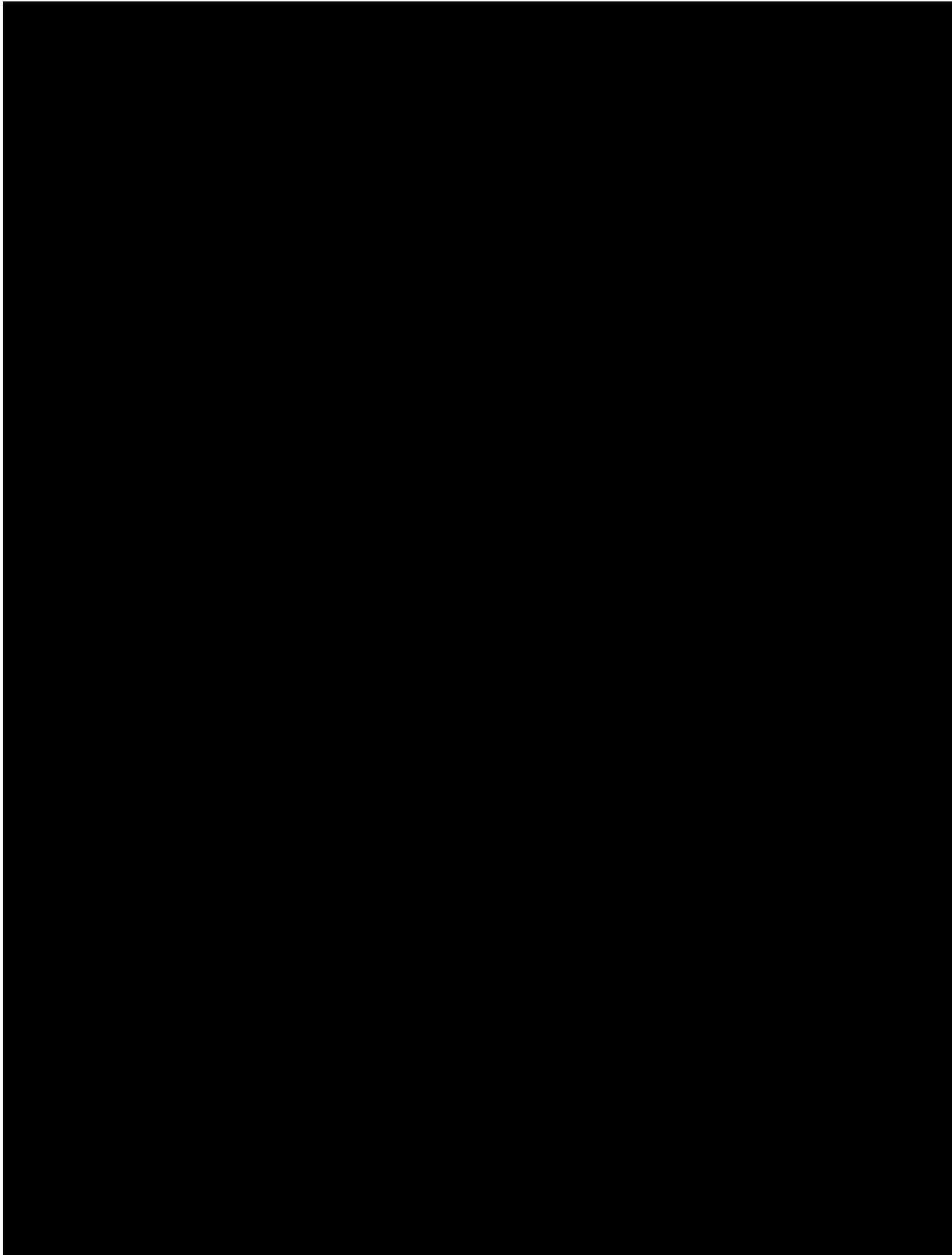
## Session 2

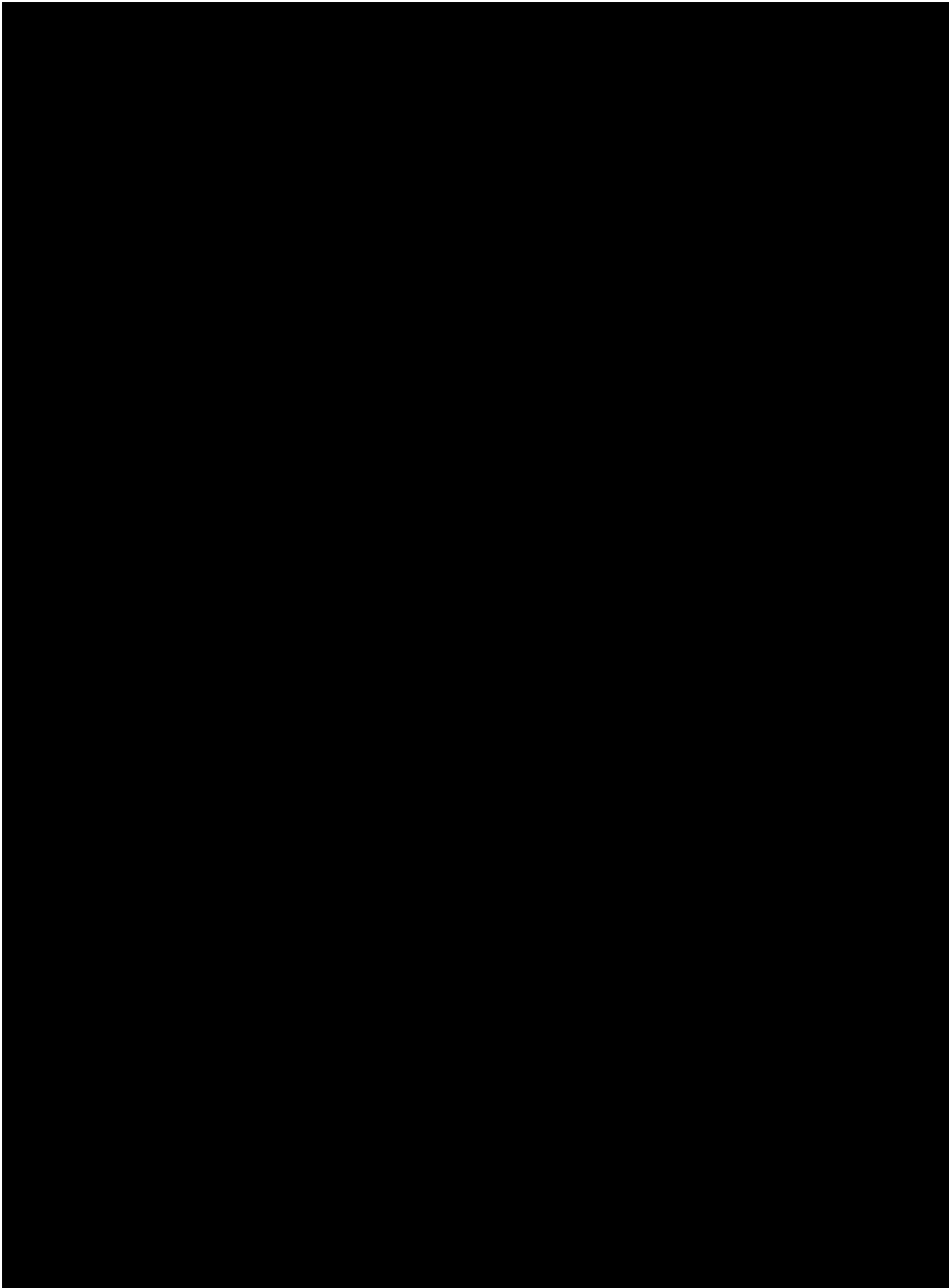


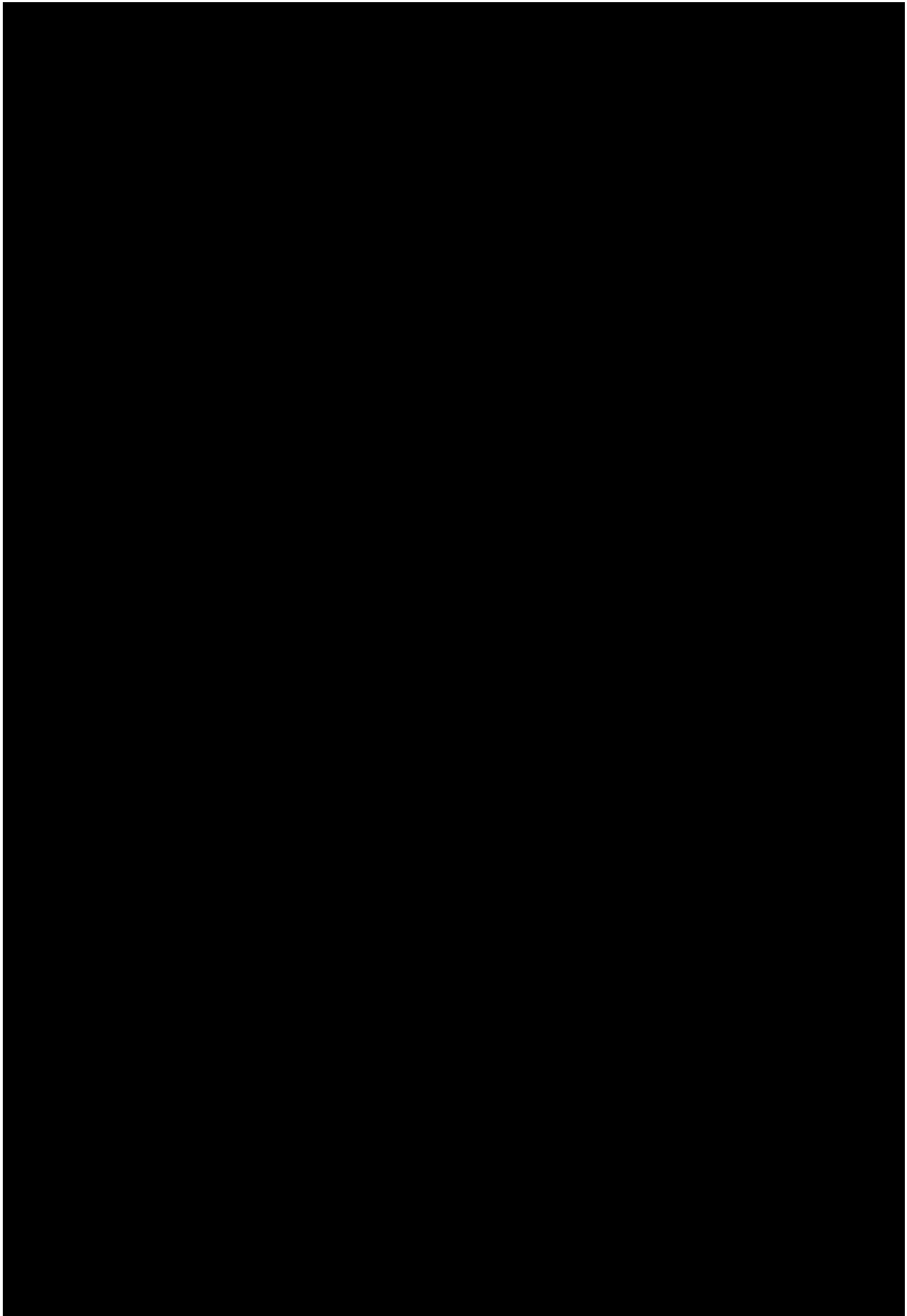












# “Mind and Body Matters”

A forum for sharing experiences, providing basic skills and information helping you to adjust to your diagnosis, manage your treatment and increase your coping skills.

















































































**WHAT HAVE I LEARNT TODAY?**

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**ABOUT SYMPTOMS OF STRESS?** \_\_\_\_\_

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...A

**BOUT HOW STRESS CAN AFFECT YOUR RENAL DISEASE?** \_\_\_\_\_

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...S

**LEEP MANAGEMENT AND RELAXATION TECHNIQUES?** \_\_\_\_\_

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**...ABOUT LEADING A BALANCED LIFE AND LEARNIING TO COPE?** \_\_\_\_\_

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**...ABOUT COMMUNICATING WITH YOUR HEALTH PROFESSIONALS AND INVOLVING YOUR FAMILY?** \_\_\_\_\_

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## Appendix 6: Pre and Post Patient Questionnaires

### 'Mind and Body Matters'

#### Session 1: 'Adjusting to your diagnosis' Pre-session form.

We would be very grateful if you would be able to provide us with some background information about your knowledge and expectations of the 'Mind and Body Matters' group. This information will help us continually improve the service. Please help us by completing this form as much as possible.

How long have you known about your kidney problems?

<1 month     1-6 months     7-12 months     >1 year

Have you attended a 'Mind and Body Matters' group before (either session 1 or 2)?

Yes                       No

**Please indicate your response to the following statements.**

	<i>Very good</i>	<i>Quite good</i>	<i>In between</i>	<i>Quite poor</i>	<i>Very poor</i>
1) How would you rate your current knowledge of kidney disease?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Very well</i>	<i>Quite Well</i>	<i>In between</i>	<i>Not very well</i>	<i>Not at all well</i>
2) How well do you feel you are adjusting to your diagnosis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) How well do you feel you understand the importance of attending your appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) How well do you feel you understand the importance of taking your medication?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) How well do you feel you are currently managing in take your medication as prescribed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) How well do you feel you are currently managing in attending your hospital appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) How well do you feel you are currently coping with your kidney problems in general?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) How well do you think you will be able to cope with your kidney problems in the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**PLEASE TURN OVER TO COMPLETE QUESTIONNAIRE**

9) How motivated are you to change your lifestyle to help improve your health? **Please ring the appropriate number.**

(1="I have not thought about it" → 10="I have already made steps toward changing my lifestyle to improve my health")

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

10) How confident do you feel you will be able to continue the self-management of your treatment (i.e. taking medication, attending appointments and maintaining lifestyle changes such as diet) in your everyday life? **Please ring the appropriate number.**

(1= "I do not feel confident in continuing → 10= "I feel extremely confident in continuing my self-management")

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

11) What do you hope you will learn from this group?

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**THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE**

## 'Mind and Body Matters'

### Session 1: 'Adjusting to your diagnosis' Feedback form.

We would be very grateful if you would be able to provide us with some feedback about session 1: 'Adjusting to your diagnosis'. Please help us improve the service by completing this form as much as possible.

**Please indicate how much you agree/disagree with the following statements.**

<i><u>During the workshop</u></i>	<i>Agree a lot</i>	<i>Agree a little</i>	<i>In between</i>	<i>Disagree a little</i>	<i>Disagree a lot</i>
1) I feel that this workshop has helped me improve my knowledge about kidney disease.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) I feel that this workshop has helped me come to terms with and adjust to my diagnosis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) This workshop has helped me gain a better understanding of why I should regularly attend my appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) This workshop has helped me gain a better understanding of why I should take my medication as prescribed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) I feel that this workshop has provided me with tips on how I can take my medication and incorporate treatment into everyday life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) The knowledge I have gained today will help me cope better with my kidney problems in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i><u>Overall Experience</u></i>	<i>Agree a lot</i>	<i>Agree a little</i>	<i>In between</i>	<i>Disagree a little</i>	<i>Disagree a lot</i>
7) I had the opportunity to listen and share my experiences with other patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) I was provided with the opportunity to ask questions that concerned me during the workshop.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) I feel able to request further support from my health care team if I require it in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) The workshop met my expectations overall.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11) I was satisfied with the workshop overall.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12) I was confident that my facilitator was well informed about kidney disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**PLEASE TURN OVER TO COMPLETE FEEDBACK**





	<i>A lot</i>	<i>A little</i>	<i>Not sure</i>	<i>Hardly any</i>	<i>None at all</i>
5) How well do you feel you are currently able to balance work, leisure, your health and rest/relaxation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u><i>Communication with health professionals</i></u>	<i>All of the time</i>	<i>Most of the time</i>	<i>In between</i>	<i>Not very often</i>	<i>Not at all</i>
6) How much of the time do you feel you can confidently ask your doctor or nurse questions about your condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u><i>Future coping</i></u>	<i>Very well</i>	<i>Quite well</i>	<i>Not sure</i>	<i>Not very well</i>	<i>Not at all well</i>
7) How well do you think you will be able to cope with your kidney problems in the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8) How motivated are you to change your lifestyle to help reduce 'stress'?

**Please ring the appropriate number.**

(1="I have not thought about it" → 10="I have already made steps toward changing my lifestyle and reducing stress")

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

9) How confident do you feel you will be able to manage 'stress' in your daily life?

**Please ring the appropriate number.**

(1= "I do not feel confident at all" → 10= "I feel extremely confident")

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

10) What do you hope you will learn from this group?

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**THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE**

**‘Mind and Body Matters’**

**Session 2: ‘Skills for managing stress and developing coping strategies’  
Feedback form.**

We would be very grateful if you would be able to provide us with some feedback about session 2: ‘Skills for managing stress and developing coping strategies’. Please help us improve the service by completing this form as much as possible.

**Please indicate your response to the following statements.**

<i><u>Coping</u></i>	<i>Definitely agree</i>	<i>Mildly agree</i>	<i>In between</i>	<i>Mildly disagree</i>	<i>Strongly disagree</i>
1) This workshop has provided me knowledge to cope better with my kidney problems in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i><u>Stress, low mood, anxiety</u></i>					
2) This workshop has helped me identify symptoms of stress, anxiety and low mood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) This session has provided me with a good understanding of how stress, anxiety and low mood can affect my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i><u>Sleep, relaxation and balancing life</u></i>					
4) This workshop has helped me learn about sleep management strategies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) This workshop has helped me learn some relaxation techniques.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) This workshop has helped me learn about pacing and balancing work, leisure, my health and rest/relaxation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i><u>Communication with health professionals</u></i>					
7) I feel more confident in being able to communicate my concerns and ask questions to my doctor or nurse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**PLEASE TURN OVER TO COMPLETE FEEDBACK**



<i>Overall Experience</i>	<i>Definitely agree</i>	<i>Mildly agree</i>	<i>In between</i>	<i>Mildly disagree</i>	<i>Strongly disagree</i>
8) I had the opportunity to listen and share my experiences with other patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) I was provided with the opportunity to ask questions that concerned me during the workshop.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) The workshop met my expectations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11) I was satisfied with the workshop overall.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12) I was confident in my facilitator's knowledge of stress, anxiety and low mood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13) How motivated are you to change your lifestyle to help reduce 'stress'?

**Please ring the appropriate number.**

**(1="I have not thought about it" → 10="I have already made steps toward changing my lifestyle and reducing stress")**

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

14) How confident do you feel you will be able to manage 'stress' in your daily life?

**Please ring the appropriate number.**

**(1= "I do not feel confident at all" → 10= "I feel extremely confident")**

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

15) What did you find the most helpful?

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16) What do you think could be improved the most?

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## **‘Mind and Body Matters’**

### **Session 1: ‘Adjusting to your diagnosis’ Pre-session form for carers.**

We would be very grateful if you would be able to provide us with some background information about your knowledge and expectations of the ‘Mind and Body Matters’ group. This information will help us continually improve the service. Please help us by completing this form as much as possible.

The person I support/care for is my:

Husband/wife/partner       Parent       Friend/neighbour   
 Son/daughter       Other Relative       Other

Have you attended a ‘Mind and Body Matters’ group before (either session 1 or 2)?

Yes       No

**Please indicate your response to the following statements.**

	<i>Very good</i>	<i>Quite good</i>	<i>In between</i>	<i>Quite poor</i>	<i>Very poor</i>
1) How would you rate your current knowledge of kidney disease?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Very much</i>	<i>A lot</i>	<i>In between</i>	<i>Not so much</i>	<i>Very little</i>
2) How much do you feel your friend/partner/relative’s diagnosis affects you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Very involved</i>	<i>Quite involved</i>	<i>In between</i>	<i>Not very involved</i>	<i>Not at all involved</i>
3) How involved do you feel in your friend/partner/relative’s healthcare?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Very important</i>	<i>Quite important</i>	<i>In between</i>	<i>Not very important</i>	<i>Not at all important</i>
4) How important do you feel it is to understand your friend/partner/relative’s health problems in general?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Very well</i>	<i>Quite Well</i>	<i>In between</i>	<i>Not very well</i>	<i>Not at all well</i>
5) How well do you <u>currently</u> feel you will be able to help your friend/partner/relative cope with their kidney problems in the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**PLEASE TURN OVER TO COMPLETE QUESTIONNAIRE**

6) What roles do you have in supporting/caring for your friend/partner/relative?  
Tick all that apply:

- |  |                          |                                   |                          |
|--|--------------------------|-----------------------------------|--------------------------|
| Accompanying them to appointments              | <input type="checkbox"/> | Organising appointments           | <input type="checkbox"/> |
| Helping them take medication                   | <input type="checkbox"/> | Gaining information about illness | <input type="checkbox"/> |
| Reminding them to take medication              | <input type="checkbox"/> | Provide physical support          | <input type="checkbox"/> |
| Provide emotional support                      | <input type="checkbox"/> | Cooking and cleaning roles        | <input type="checkbox"/> |
| Other <input type="checkbox"/> (please state): |                          |                                   |                          |

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7) How motivated are you to involve yourself in your friend/partner/relative's changes in lifestyle and illness management? **Please ring the appropriate number.**

(1="I do not think I should" → 10="I have already made steps toward  
getting involved" involving myself in changes")

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

8) How confident do you feel you will be able to continue supporting/caring for your friend/partner/relative in your everyday life? **Please ring the appropriate number.**

(1= "I do not feel at all confident" → 10= "I feel extremely confident")

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

9) What do you hope you will learn from this group?

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**THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE**

## 'Mind and Body Matters'

### Session 1: 'Adjusting to your diagnosis' Feedback form for carers.

We would be very grateful if you would be able to provide us with some feedback about session 1: 'Adjusting to your diagnosis'. Please help us improve the service by completing this form as much as possible.

**Please indicate how much you agree/disagree with the following statements.**

<i><u>During the workshop</u></i>	<i>Agree a lot</i>	<i>Agree a little</i>	<i>In between</i>	<i>Disagree a little</i>	<i>Disagree a lot</i>
1) I feel that this workshop has helped me improve my knowledge about kidney disease.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) I feel that this workshop has helped me come to terms with and adjust to my friend/partner/relative's diagnosis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) I feel more involved in my friend/partner/relative's healthcare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) I feel that this workshop has provided me with tips on how I can support/care for my friend/partner/relative in incorporating treatment into their everyday life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) The knowledge I have gained today will help me cope better with my friend/partner/relative's illness in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i><u>Overall Experience</u></i>	<i>Agree a lot</i>	<i>Agree a little</i>	<i>In between</i>	<i>Disagree a little</i>	<i>Disagree a lot</i>
6) I had the opportunity to listen and share my experiences with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) I was provided with the opportunity to ask questions that concerned me during the workshop.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) I feel able to request further support if I require it in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) The workshop met my expectations overall.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) I was satisfied with the workshop overall.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11) I was confident that my facilitator was well informed about kidney disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**PLEASE TURN OVER TO COMPLETE FEEDBACK**

12) How motivated are you to involve yourself in your friend/partner/relative's changes in lifestyle and illness management? **Please ring the appropriate number.**

(1="I do not think I should → 10="I have already made steps toward  
get involved" involving myself in changes")

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

13) How confident do you feel you will be able to continue supporting/caring for your friend/partner/relative in your everyday life? **Please ring the appropriate number.**

(1= "I do not feel at all confident → 10= "I feel extremely confident")

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

15) What did you find the most helpful?

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16) What do you think could be improved the most?

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17) Other general comments?

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**THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE**

## 'Mind and Body Matters'

### Session 2: 'Skills for managing stress and developing coping strategies' Pre-session form.

We would be very grateful if you would be able to provide us with some background information about your knowledge and expectations of the 'Mind and Body Matters' group. This information will help us continually improve the service. Please help us by completing this form as much as possible.

The person I support/care for is my:

Husband/wife/partner  Parent  Friend/neighbour   
 Son/daughter  Other Relative  Other

Have you attended a 'Mind and Body Matters' group before (either session 1 or 2)?

Yes  No

**Please indicate your response to the following statements.**

	<i>Very good</i>	<i>Quite good</i>	<i>In between</i>	<i>Quite poor</i>	<i>Very poor</i>
1) How would you rate your current knowledge of kidney disease?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Very much</i>	<i>A lot</i>	<i>In between</i>	<i>Not so much</i>	<i>Very little</i>
2) How much do you feel your friend/partner/relative's diagnosis affects your emotional wellbeing and stress levels?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Very involved</i>	<i>Quite involved</i>	<i>In between</i>	<i>Not very involved</i>	<i>Not at all involved</i>
3) How involved do you feel in your friend/partner/relative's healthcare?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Very important</i>	<i>Quite important</i>	<i>In between</i>	<i>Not very important</i>	<i>Not at all important</i>
4) How important do you feel it is to understand your friend/partner/relative's emotional wellbeing and health problems in general?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Very well</i>	<i>Quite Well</i>	<i>In between</i>	<i>Not very well</i>	<i>Not at all well</i>
5) How well do you <u>currently</u> feel you will be able to help your friend/partner/relative cope with their kidney problems in the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**PLEASE TURN OVER TO COMPLETE QUESTIONNAIRE**

6) What roles do you have in supporting/caring for your friend/partner/relative?  
**Tick all that apply:**

- |  |                          |                                   |                          |
|--|--------------------------|-----------------------------------|--------------------------|
| Accompanying them to appointments              | <input type="checkbox"/> | Organising appointments           | <input type="checkbox"/> |
| Helping them take medication                   | <input type="checkbox"/> | Gaining information about illness | <input type="checkbox"/> |
| Reminding them to take medication              | <input type="checkbox"/> | Provide physical support          | <input type="checkbox"/> |
| Provide emotional support                      | <input type="checkbox"/> | Cooking and cleaning roles        | <input type="checkbox"/> |
| Other <input type="checkbox"/> (please state): |                          |                                   |                          |

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7) How motivated are you to involve yourself in your friend/partner/relative's emotional health and illness management? **Please ring the appropriate number.**

(1="I do not think I should → 10="I have already made steps toward  
get involved" involving myself")

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

8) How confident do you feel you will be able to continue supporting/caring for your friend/partner/relative in your everyday life? **Please ring the appropriate number.**

(1= "I do not feel at all confident → 10= "I feel extremely confident"

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

9) What do you hope you will learn from this group?

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**THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE**



## 'Mind and Body Matters'

### Session 2: 'Skills for managing stress and developing coping strategies' Feedback form.

We would be very grateful if you would be able to provide us with some feedback about session 2: 'Skills for managing stress and developing coping strategies'. Please help us improve the service by completing this form as much as possible.

**Please indicate how much you agree/disagree with the following statements.**

<i><u>During the workshop</u></i>	<i>Agree a lot</i>	<i>Agree a little</i>	<i>In between</i>	<i>Disagree a little</i>	<i>Disagree a lot</i>
1) I feel that this workshop has provided me with knowledge to help me support my friend/partner/relative to manage stress, anxiety and low mood in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) This workshop has provided me with strategies to help me manage my own stress in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) This workshop has encouraged me to take care of my own emotional wellbeing through sleep management, relaxation and balancing work, leisure and health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) I feel more involved in my friend/partner/relative's healthcare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) I feel more confident in being able to communicate my concerns and ask questions to my friend/partner/relative's doctor or nurse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i><u>Overall Experience</u></i>	<i>Agree a lot</i>	<i>Agree a little</i>	<i>In between</i>	<i>Disagree a little</i>	<i>Disagree a lot</i>
6) I had the opportunity to listen and share my experiences with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) I was provided with the opportunity to ask questions that concerned me during the workshop.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) I feel able to request further support if I require it in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) The workshop met my expectations overall.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) I was satisfied with the workshop overall.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11) I was confident that my facilitator was well informed about kidney disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**PLEASE TURN OVER TO COMPLETE FEEDBACK**

12) How motivated are you to involve yourself in your friend/partner/relative's emotional health and illness management? **Please ring the appropriate number.**

(1=“I do not think I should → 10=“I have already made steps toward  
get involved” involving myself”)

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

13) How confident do you feel you will be able to continue supporting/caring for your friend/partner/relative in your everyday life? **Please ring the appropriate number.**

(1= “I do not feel at all confident → 10= “I feel extremely confident”

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

14) What did you find the most helpful?

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15) What do you think could be improved the most?

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16) Other general comments?

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**THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE**

## Appendix 7: Meetings

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### Mind and Body Matters Initial meeting

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**Date:** 15/11/2012

**Present:** XXXXXX XXXXXX (Assistant Clinical Psychologist); XXXXXX  
 XXXXXX (Lead Clinical Nurse Specialist) XX XXXXXX  
 XXXXXX(Consultant Clinical Psychologist)

**Apologies:** XXXXXX XXXXXX (Consultant Nurse Specialist)

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	<b>Agenda item</b>	<b>Discussion points</b>	<b>Actions / Responsible</b>
1.	Gaps in current patient info forum	<ul style="list-style-type: none"> <li>- Discussed current feedback on patient info forum provided by Cons Nurse Spec to Cons Clin Psych and Low Clearance MDT.</li> <li>- Lead Nurse Spec discussed with psych team potential routes forward</li> <li>- All agreed Asst Psych would look into possible literature relating to improving Low Clearance pt education</li> </ul>	Assistant Clin Psych

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**Mind and Body Matters Pre-Workshops meeting**

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**Date:** 06/05/2011

**Present:** XXXXXX XXXXXX (Assistant Clinical Psychologist); XXXXXX  
 XXXXXX (Lead Clinical Nurse Specialist)

**Apologies:** XX XXXXXX XXXXXX(Consultant Clinical Psychologist)

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	<b>Agenda item</b>	<b>Discussion points</b>	<b>Actions / Responsible</b>
2.	Workshop material	- Final review of workshop material agreed for session 1 and 2 Review of pre and post feedback forms	No further action
3.	Referrals	- Discussions around number of referrals of patients and carers	No Further action
4.	Admin	- Update on transport requirements and room bookings	No further action
5.	Dates for further workshops	- According to number of referrals received, agreed on future dates of workshops	Lead Clin Nurse Spec to finalise dates

## Mind and Body Matters final Meeting

**Date:** 01/03/12

**Present:** XXXXXX XXXXXX (Assistant Clinical Psychologist); XXXXXX  
XXXXXX (Lead Clinical Nurse Specialist)

**Apologies:** XX XXXXXX XXXXXX(Consultant Clinical Psychologist)

	<b>Agenda item</b>	<b>Discussion points</b>	<b>Actions / Responsible</b>
6.	Review of feedback received	<ul style="list-style-type: none"> <li>- Continue to receive positive feedback from attendees.</li> <li>- participants reporting an increase in knowledge of ESRD and confidence in applying adherence and psychological wellbeing strategies.</li> <li>- Sleep and relaxation strategies received very positive feedback.</li> <li>- Both agreed the sessions themselves went well and met participant expectations.</li> </ul>	Assistant Psychologist
7.	Achievements and limitations of workshops	<ul style="list-style-type: none"> <li>- Reminder that the main aim of the Mind and Body Matters pilot was to: "help patients who are in the transition period from diagnosis to ESRD to cope better through general education about their illness and the advantages of enhancing their psychological and physical self-management."</li> <li>- Both that the main aim of the pilot was achieved and that the goal to develop a programme involving key psychological components for LC patients to compliment the patient information forum was also achieved.</li> <li>- Other achievements included raising awareness of the deficit in educational needs for patients. Mind and Body Matters has raised the profile of the importance of education presented in a way that is acceptable to patients to the rest of the renal team.</li> <li>- Assistant Psych highlighted the lack of administrative time and resources within psychology.</li> <li>- The waiting list issue was discussed. To be able to run regular sessions with adequate numbers of patients a regular recruitment pattern needs to be established i.e. regular database searches and updates of new patients, sending out information leaflets offering opt-in to sessions, compiling and organising dates for sessions, regular room bookings and</li> </ul>	No further action

		<p>refreshments. These required more time and resources than currently available.</p> <ul style="list-style-type: none"> <li>- Clin Nurse Spec raised the problem with limited clinician time, highlighting that this had even pushed back this meeting till March when it was supposed to be held in January.</li> </ul>	
8.	Clinician Workload and Resources/Departmental changes	<ul style="list-style-type: none"> <li>- Following on from Clin Nurse Spec raising a problem with limited clinician time, departmental changes were discussed including the current drive to distribute clinicians into community bases meaning that both psychologists and LC nurses would spend less time at the RFH.</li> <li>- It was agreed that it would be most appropriate if we could circulate Mind and Body Matters across each site, making it more available to patients based further away. However this would require even more time and resources than was already available to ensure that it could run efficiently.</li> <li>- Despite limitations of resources Clin Nurse Spec raised that it has been acknowledged within the department the importance of patient education. From departmental seminars Mind and Body Matters had been mentioned as a useful method of enhancing self-care through education in patients.</li> </ul>	No further action required
9.	Way forward for Mind and Body Matters	<ul style="list-style-type: none"> <li>- It was agreed that the consultancy aims were met and that the consultancy could be ended.</li> <li>- Both voiced enthusiasm for the project but acknowledged the problem of lack of resources which were unlikely to change.</li> <li>- Lead clin nurse spec suggested that a self-help book format could be used as another method to introduce self-care and psychological components early to ESRD patients and that we could discuss this further as a project at a future date when departmental changes have become more steady.</li> <li>- Agreed end of meeting and consultancy</li> </ul>	No further action

# **APPENDICES: CORE UNIT**

## **4**

### **TEACHING AND**

### **TRAINING**

# MSc HEALTH PSYCHOLOGY PROGRAMME

## Appendix 1: MSc Health Promotion Teaching Plan

### MSc Health Promotion module - lecture plan 1

**Objective:** To look at Health Promotion in an applied setting - transplantation

**Time:** 3 hours

**Materials:**

- Copies of lecture slides – pre-uploaded to Moodle
- Flipchart paper and pens
- References of relevant papers (Handout for group work – if enough time)

**Training Needs and Special Requirements for students** (Discussed with module leader):

- Health Promotion Module for MSc Health Psychology Students. Topic area to be covered includes 'health promotion in the applied setting of transplantation'.
- 30-40 students in the course.
- 2 previous sessions covered introduction to health promotion and inequalities in health.
- Social cognitive models had been covered in 'Introduction to health psychology' module previously.
- One student noted to have a disability and has requested slides to be put up on Moodle before the session.

**Programme:**

20 minutes - Recap and quick health promotion quiz.

*Gage current knowledge of students and remind them of learning in previous lectures.*

*Interactive section - Students are to answer basic health promotion questions to recap knowledge and engage speaking up in session.*

20 minutes - Why is health promotion important in transplant patients?

*Introduction and overview of use of health promotion in applied setting of transplantation.*

20 minutes - Brief overview of the transplant process. [1 hour]

*Overview and background to transplantation process.*

20 minutes - Psychological evaluation for transplant candidates.

*Assessing Risk and promoting healthy futures.*

*Introduce psychological components, risk factors and clinical factors to look out for.*



*What are the health promotion areas? – time to think about what model over break*

**15 minutes - Break**

20 minutes - What model?

*Allow students time to suggest social cognition models which may be relevant to use within this applied setting. Discuss self-regulation model as an example (and most relevant model in this setting)*

20 minutes - Other areas of risk communication. [1hr 5 mins]

*Discussion of other risk factor areas that require promotion of health such as Obesity, Cancer (with use of immunosuppressant medication), Cardiovascular Disease, Diabetes*

20 minutes - Evaluation.

*Brief look at evaluation and evaluating patient experiences of having a transplant. Provide students with an opportunity to engage in their own ideas*

20 minutes – Group exercise

*Review health promotion paper. Provide students opportunity to critique a health promotion intervention. Looking specifically at health promotion models and evaluation methods.*

10 minutes – extra time left for questions and running over time frame in between sections.

**Further Reading:**

Gordon, E.J., Prohaska, T., Siminoff, L.A., Minich, P.J., Sehgal, A.R. (2005) Can focusing on Self-Care Reduce Disparities in Kidney Transplant Outcomes? *Am J Kidney Dis.* 45(5) 935-940.

Bandura, A. (2004) Health Promotion by Social Cognitive Means. *Health Education & Behaviour.* 31(2) 143-164

Salyer, J., Sneed, G., Corley, M.C. (2001) Lifestyle and Health Status in Long Term Cardiac Transplant Recipients. *Heart & Lung.* 30(6) 445-457

Lin, S-Y., Fetzer, S.J., Lee, P-C., Chen, C-H. (2011) *Journal of Clinical Nursing* 20, 3313-3321.

Bond M.A. (1998) Health promotion and disease prevention in kidney transplant recipients. *J Transpl Coord.* 8,221–224.

Talas, S.M., Bayraktar, N. (2004) Kidney transplantation: determination of the problems encountered by Turkish patients and their knowledge and practices on healthy living. *Journal of Clinical Nursing.* 13, 580-588.

Stuifbergen, A.K., Seraphine, A., Roberts, G. (2000) An Explanatory Model of Health Promotion and Quality of Life in Chronic Disabling Conditions. *Nursing Research*. 49(3) 122-129

Novotney, A. (2011) Savina lives, one organ at a time: Psychologists are helping remove barriers to organ donation. *American Psychological Association*. 42(11) 74. Retrieved from <http://www.apa.org/monitor/2011/12/organ-donation.aspx>

## **MSc Health Promotion module - lecture plan 2**

**Objective:** To look individual level interventions

**Time:** 3 hours

**Materials:**

- Copies of lecture slides – pre-uploaded to Moodle
- Flipchart paper and pens
- References of relevant papers (Handout for group work – if enough time)

**Training Needs and Special Requirements for students** (Discussed with module leader):

- Session needs to look at how health promotion is conducted at an individual level. Can look at behavioural change techniques looking at how individual level health promotion is relevant and how students can apply knowledge in real life contexts. How individual-level interventions can be designed and developed. Research examples of individual-lead interventions. How individual level interventions can be evaluated and reported. Students must be able to apply knowledge gained in session to help them develop a health promotion campaign to encourage healthy lifestyles in University students

**Programme:**

5 minutes – Outline, 'First do no harm'

*Overview of lecture topics. With word of warning to be sensitive about matters of confidentiality and others affected by chronic illness.*

10 minutes – What are individual approaches to behaviour change?

*NICE Public Health Guidance: Behaviour Change Individual Approaches, 2014*

*Introduce recommendations on individual-level behaviour change interventions to tackle a range of behaviours linked to health problems and chronic diseases e.g. CVD, DM Type II, Cancer*

5 minutes – Beattie's model, Examples of Behaviour change at different levels in healthcare

*Individual Level: smoking cessation, increasing physical activity, medication adherence.*

*Practitioner / Professional: service delivery (procedures and techniques, communication)*

*Organisation Level: adherence to guidelines, complying with policy*  
(Michie, Implementation Science Summer School, Dublin 2012)

10 minutes – Appropriate areas for health psychologists to intervene in medical settings

*Introduce 3 areas for intervention: Programmes designed to help adjustment to illness; Interventions aimed to alleviate or directly treat underlying symptoms; Programmes that help patients cope with the difficulties of medical treatments; Programmes designed to help adjustment to illness. Examples to demonstrate areas for intervention.*

15-20 minutes – Break (flexible)

40 – 45 minutes – Steps to designing individual-level interventions, including case study

*Introduce paper - The behaviour change wheel: A new method for characterising and designing behaviour change interventions - Susan Michie, Maartje M van Stralen and Robert West, 2011*

*Discuss step to designing behaviour change.*

*Use Renal Case Study to demonstrate concepts. (10-15 minutes in pairs task).*

*Include COM-B model and Behaviour Change Wheel and Behaviour Change Techniques (BCT's) students should have some understanding of behaviour change techniques.*

*Examples to demonstrate BCT's.*

*Worked example of steps: Getting GPs to deliver brief smoking cessation interventions (West & Michie, 2011, How to change behaviour: From education to enablement)*

15 – 20 minutes – Case Study small group work

*Students should attempt to design individual-level intervention for people with similar problems with adherence to treatment?*

10 – 15 minutes – The importance of Evaluation: RE-AIM

*Introduce students to the importance of evaluation as part of the process to designing individual level interventions. Use RE-AIM*

10 – 20 minutes – RE-AIM group work

*Use RE-AIM Checklist to review the journal articles following the RE-AIM framework.*

10 minutes – Summary

### **Further Reading:**

Abraham, C., & Michie, S., (2008) A taxonomy of Behaviour Change Techniques Used in Interventions. *Health Psychology*. 27(3), 379-387.

Bredin, M., Corner, J., Krishnasamy, M., Plant, H., Bailey, C., A'Hern, R., (1999) Multicentre randomised controlled for breathlessness in patients with lung cancer. *BMJ*. 318.

Cove, J., (2011) A new Approach to Psychological Support in the Renal Setting. *Journal of Renal Nursing*. 3(1).

Glasgow, R.E., Bull, Sheana, S., Gillette, C., Klesges, L.M., Dzewaltowski, D.A. (2002) Behaviour Change Intervention Research in Healthcare Settings. *American Journal of Preventative Medicine*. 23(1), 62-69.

Glasgow, R.E., Whitlock, E.P, Eakin, E.G., Lichtenstein, E., (2000) A Brief Smoking Cessation Intervention for Women in Low-Income Planned Parenthood Clinics. *American Journal of Public Health*. 90(5).

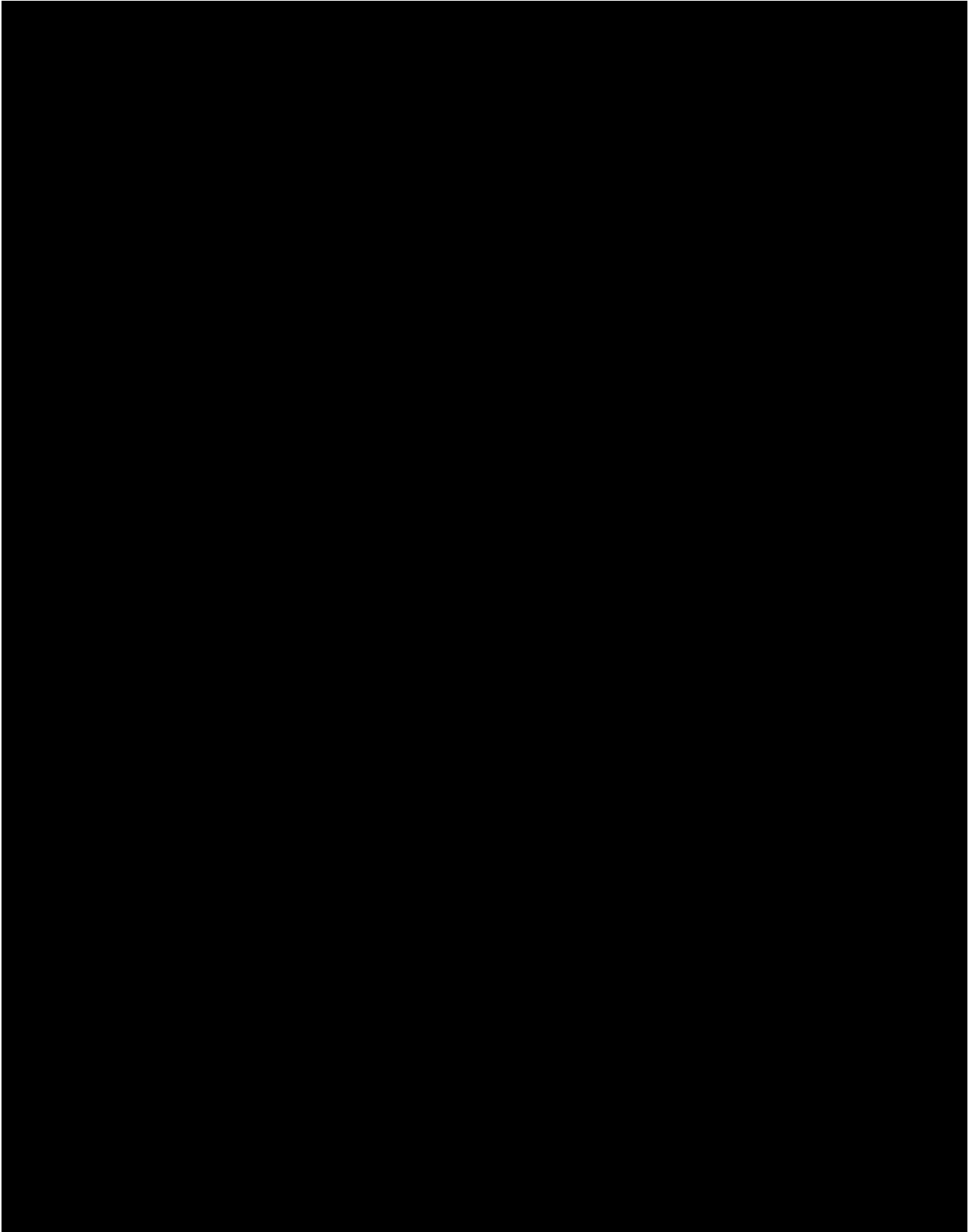
Halford, J., & Brown, T., (2009) Cognitive-Behavioural Therapy as an adjunctive Treatment in Chronic Physical Illness. *Advances in Psychiatric Treatment*. 15, 306-317.

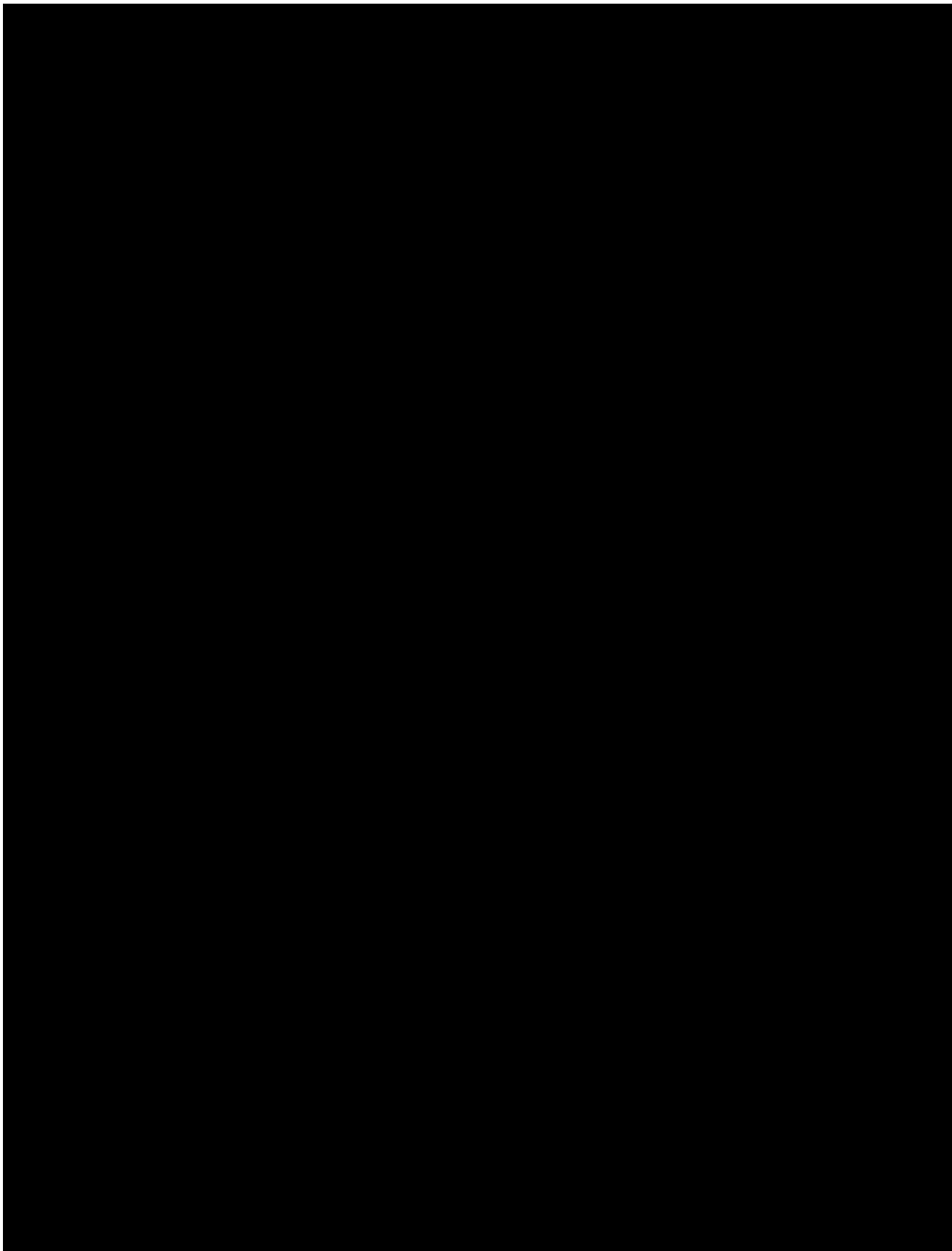
Hegeson, V.S., & Cohen, S., (1996) Social Support and Adjustment to Cancer: Reconciling Descriptive, Correlational, and Intervention Research. *Health Psychology*. 15(2), 135-148.

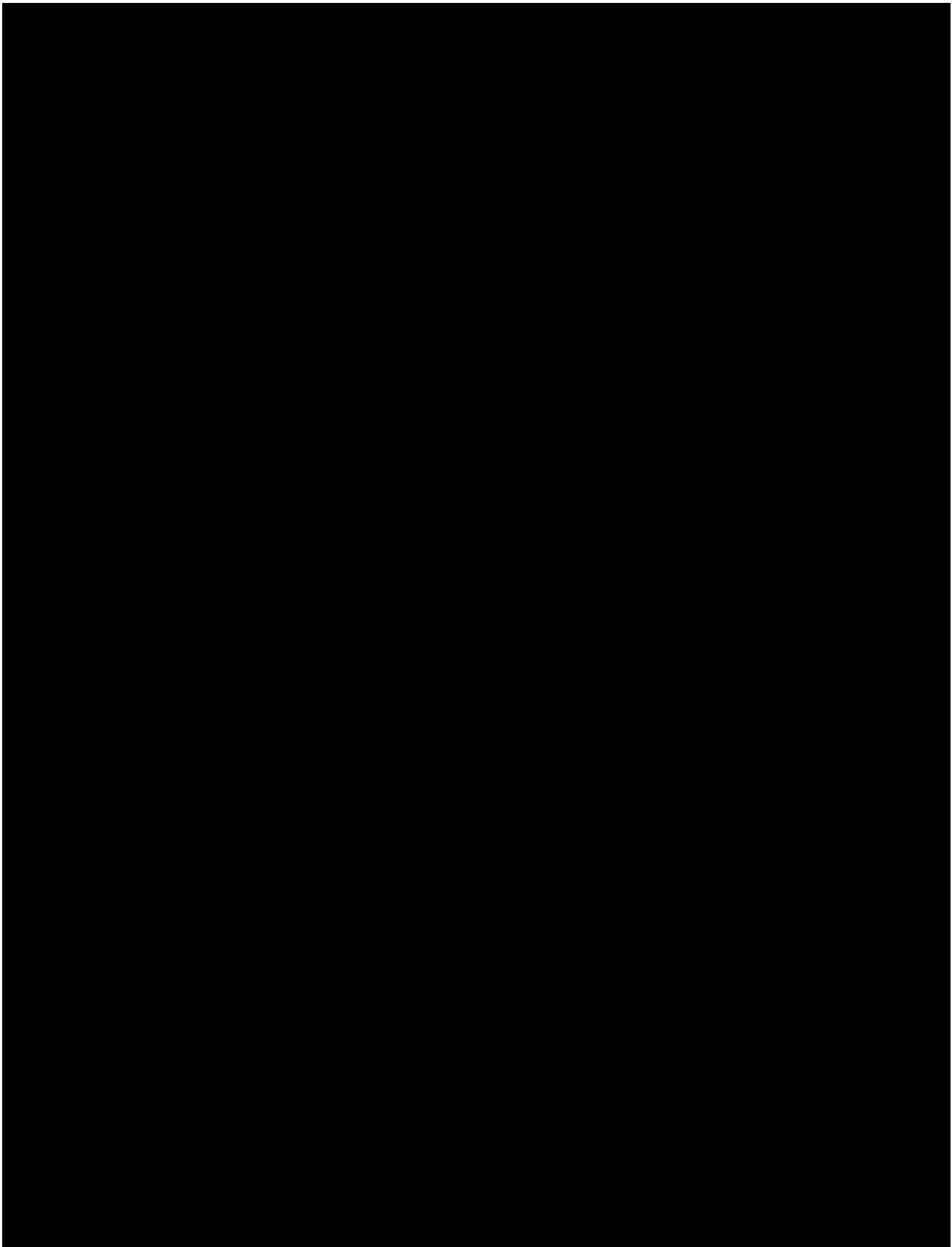
Michie, S., van Stralen, M.M., & West, R., (2011) The Behaviour Change Wheel: A New Method for Characterising and Designing Behaviour Change Interventions. *Implementation Science*. 6(42).

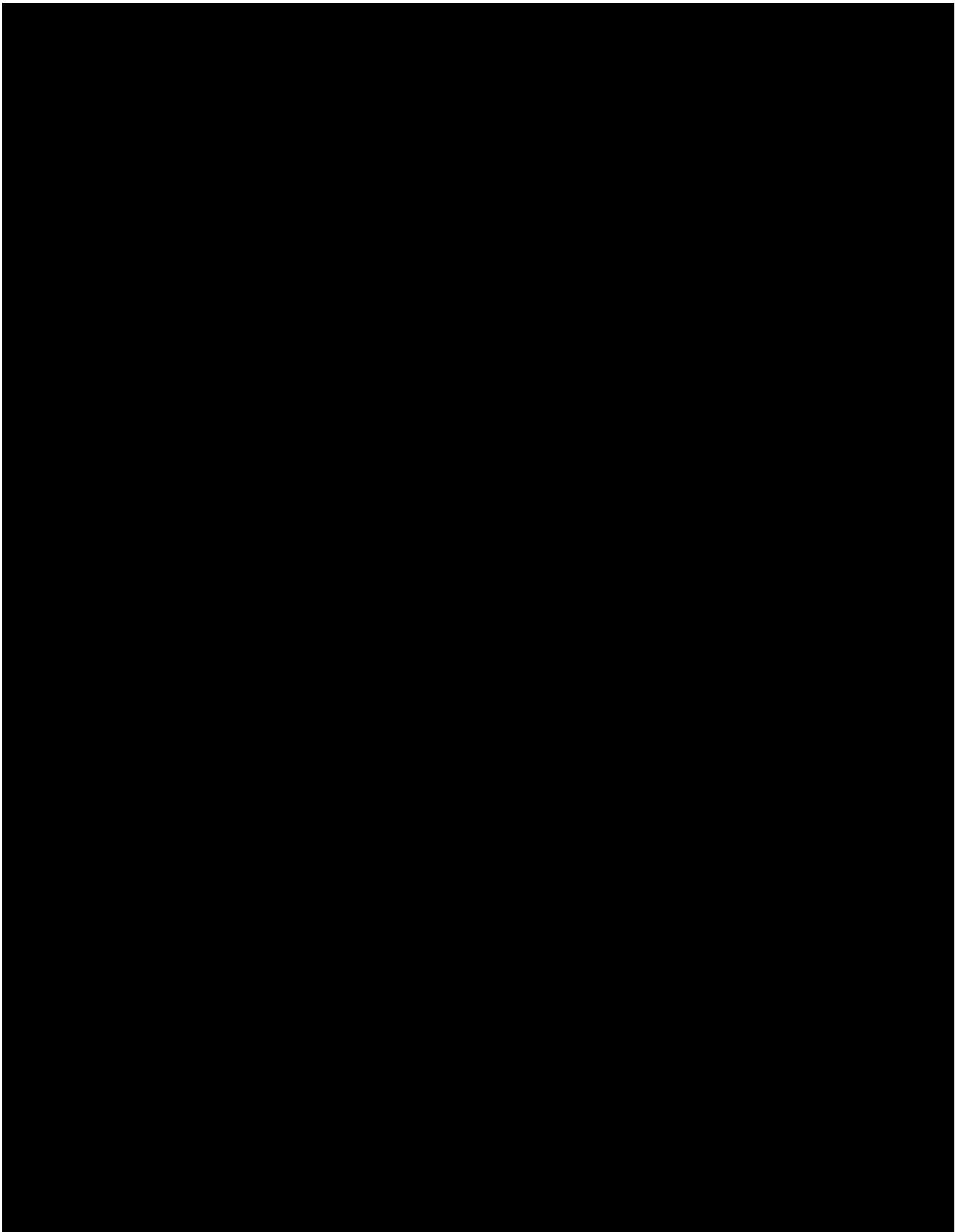
## Appendix 2: Handouts

### Lecture 1

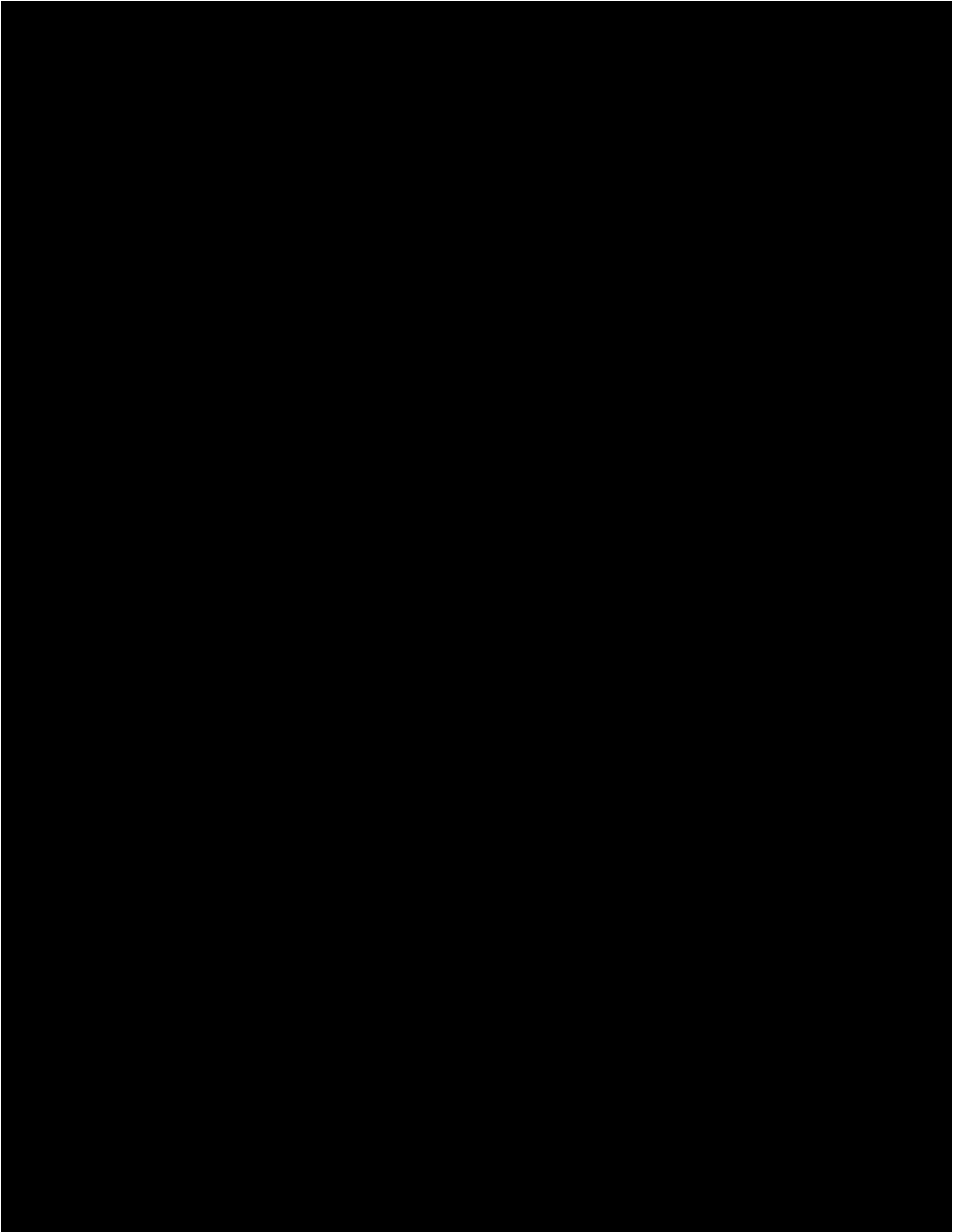


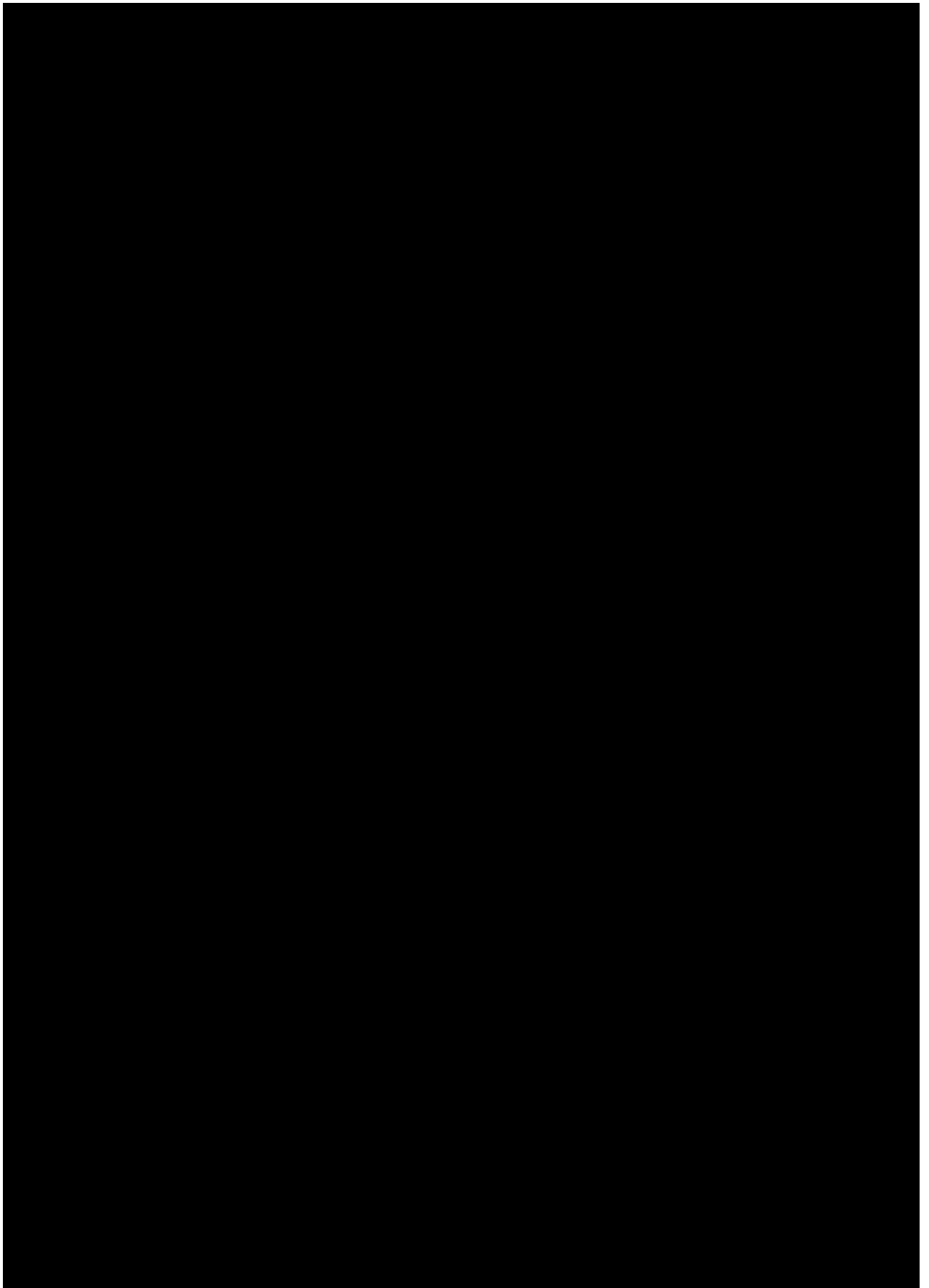






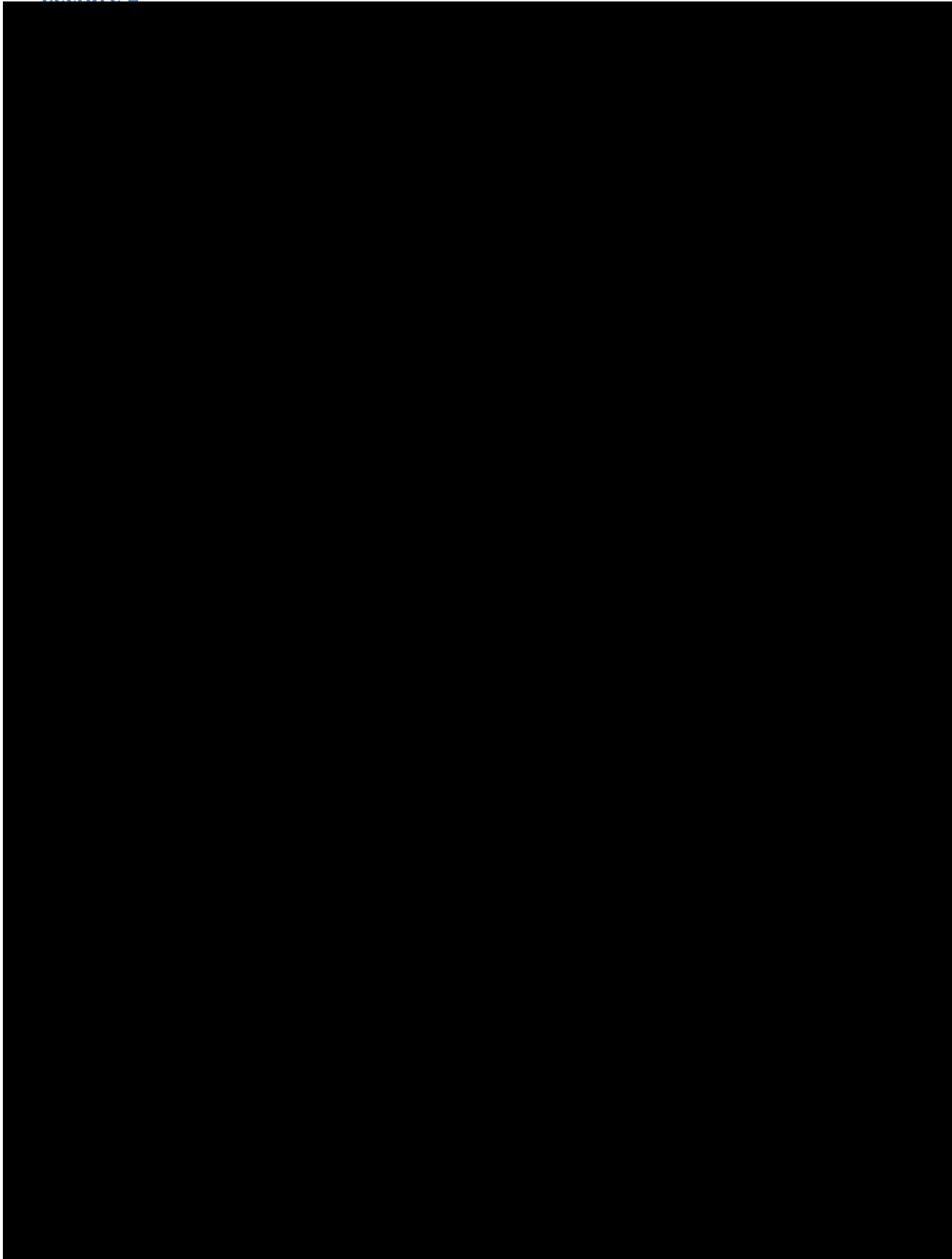


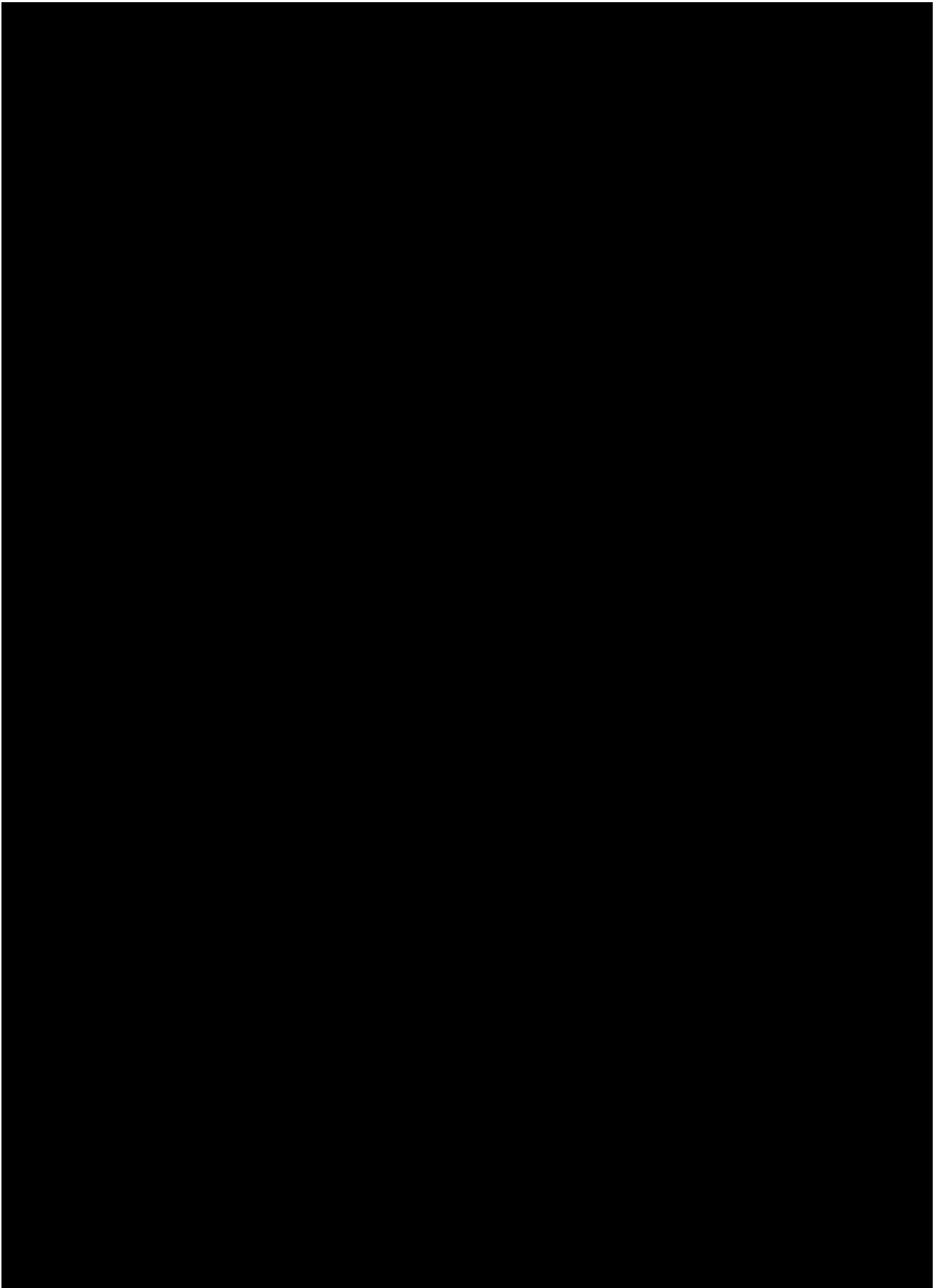


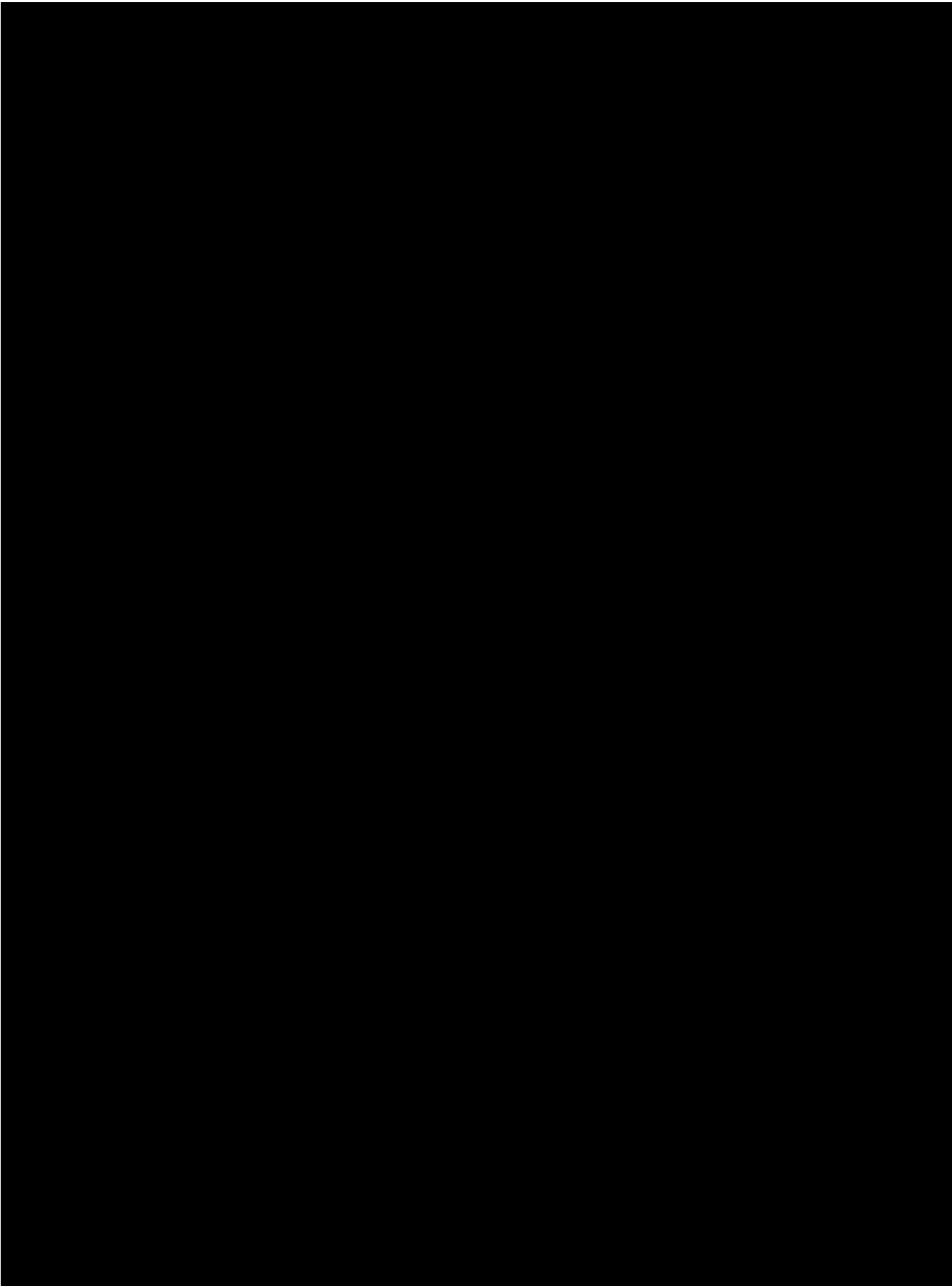


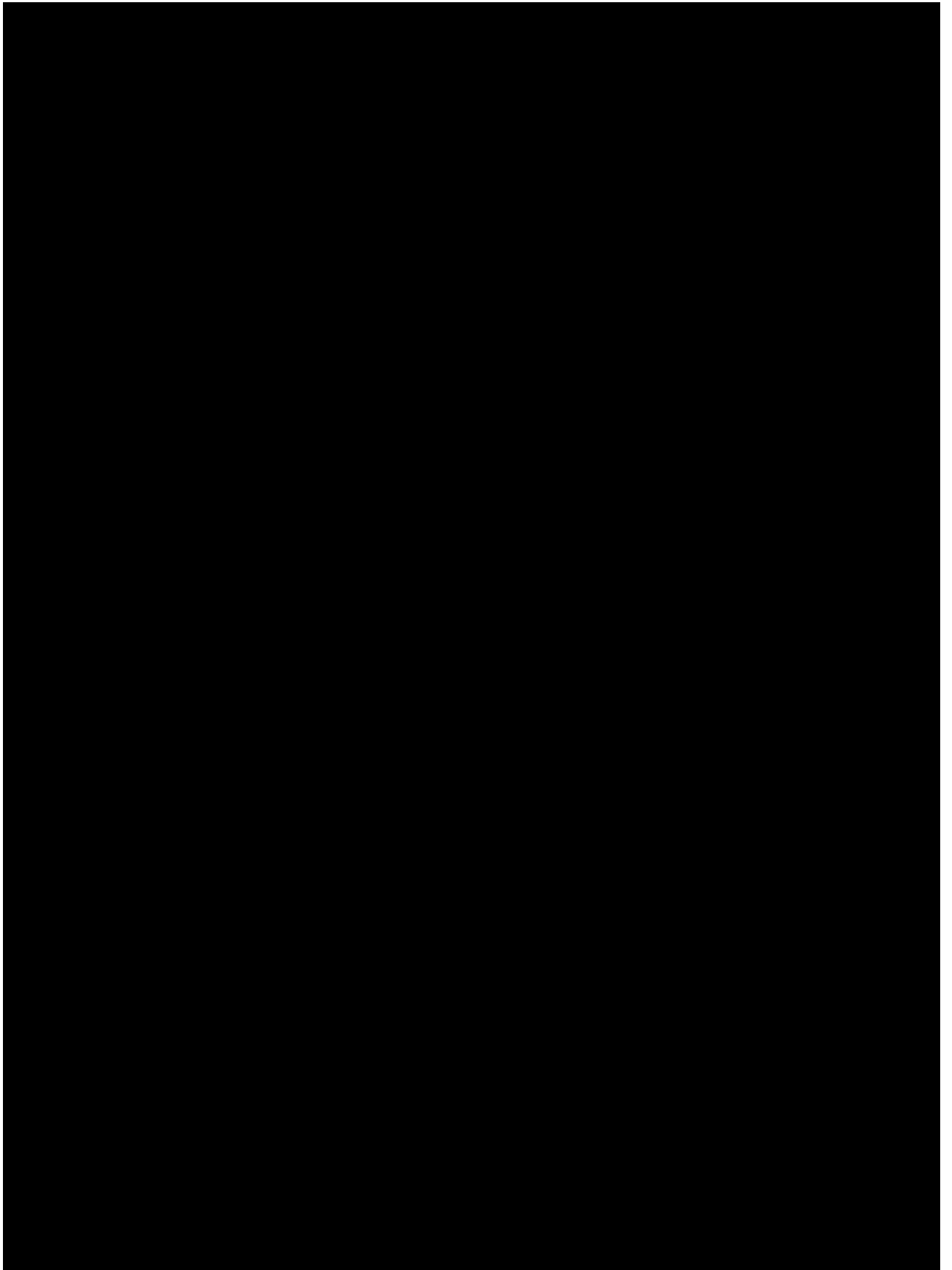


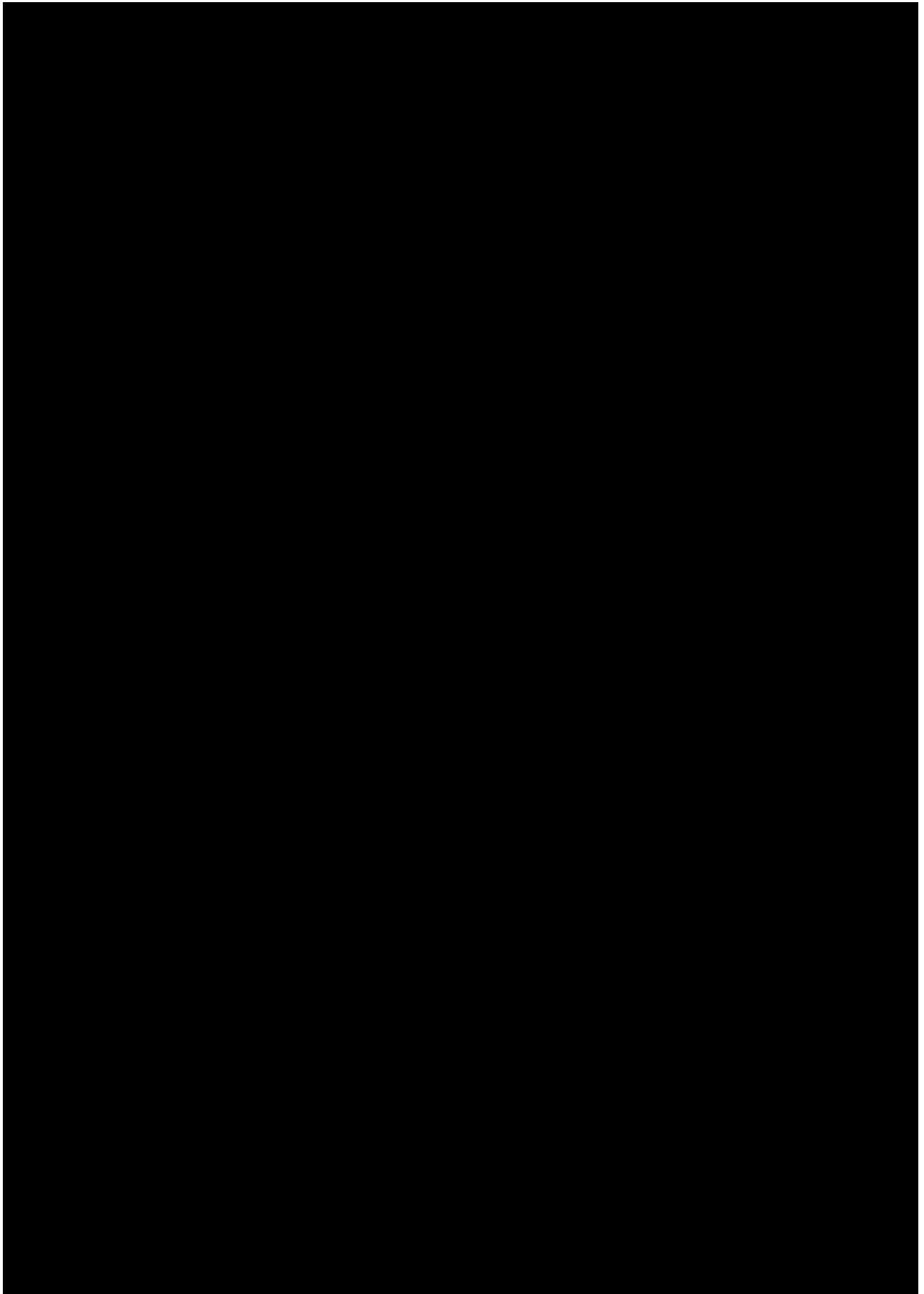
## Lecture 2



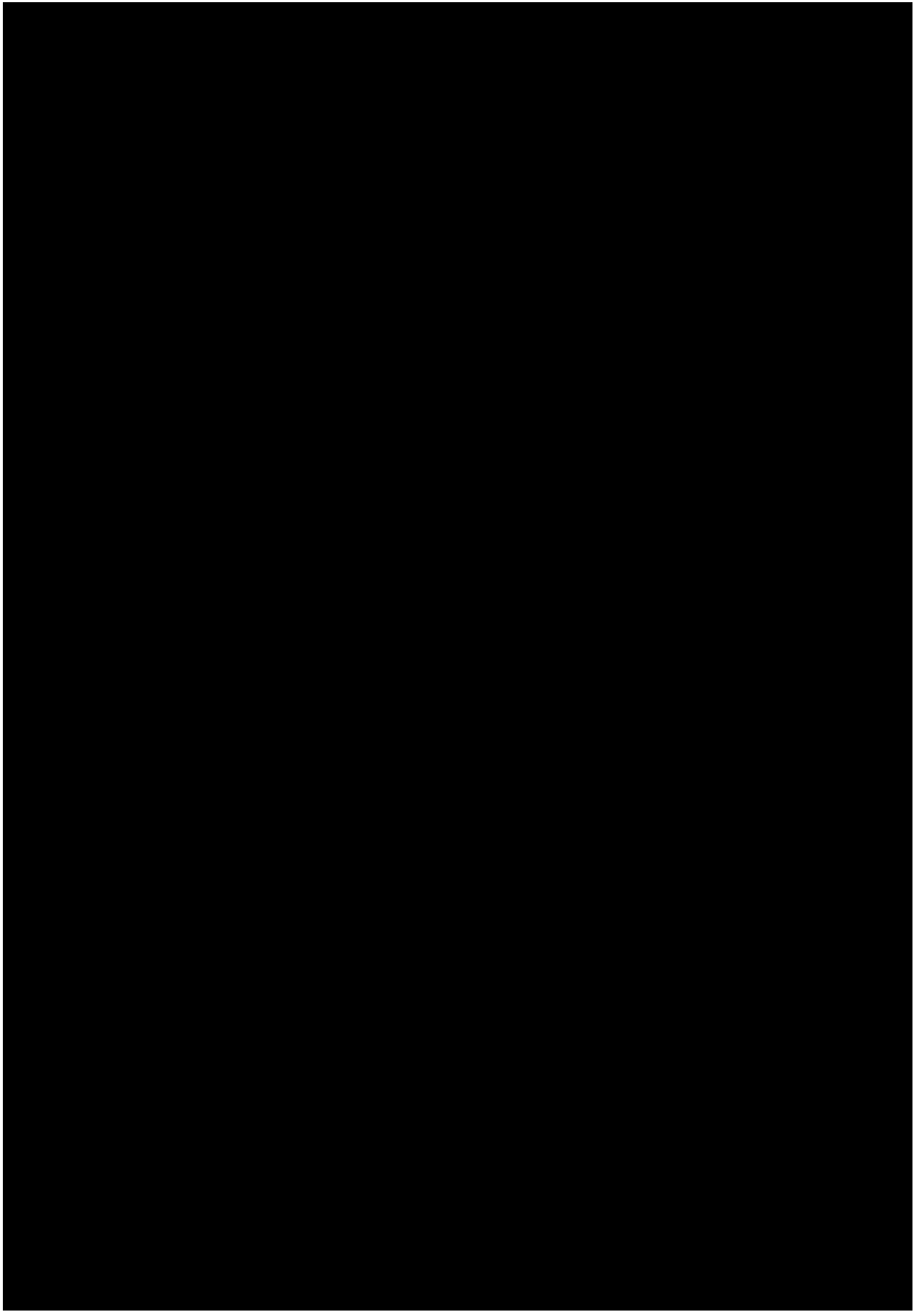


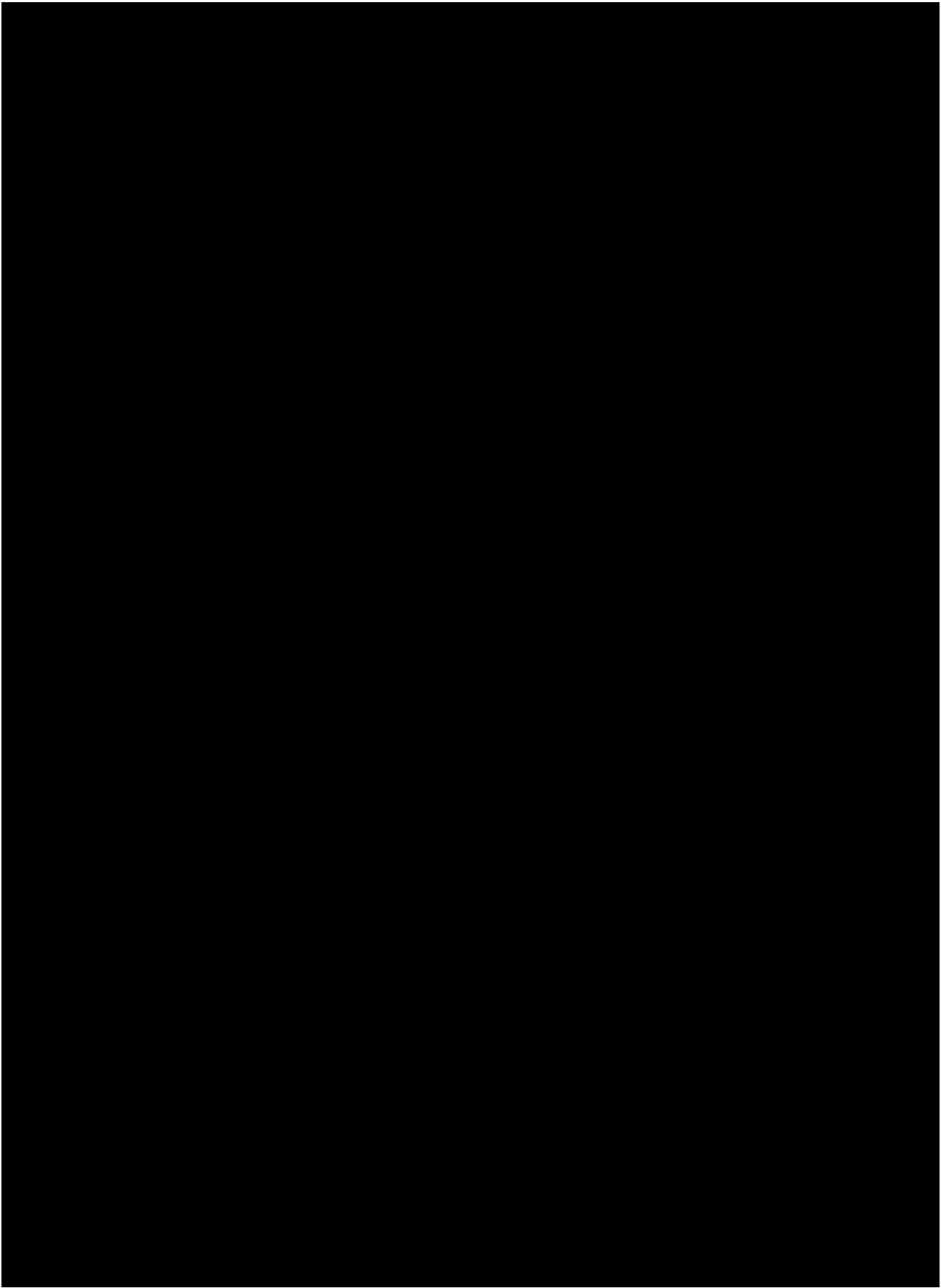


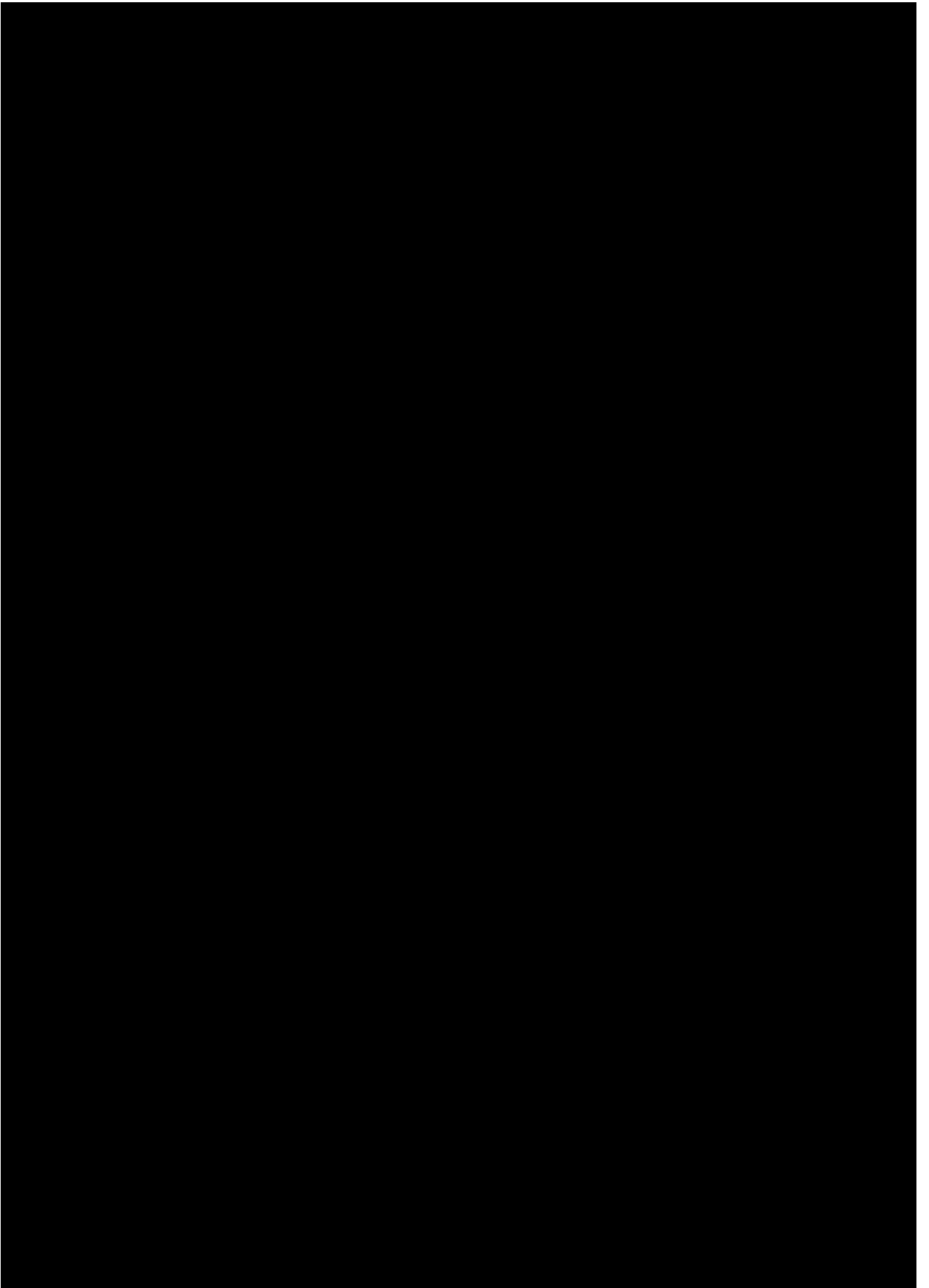


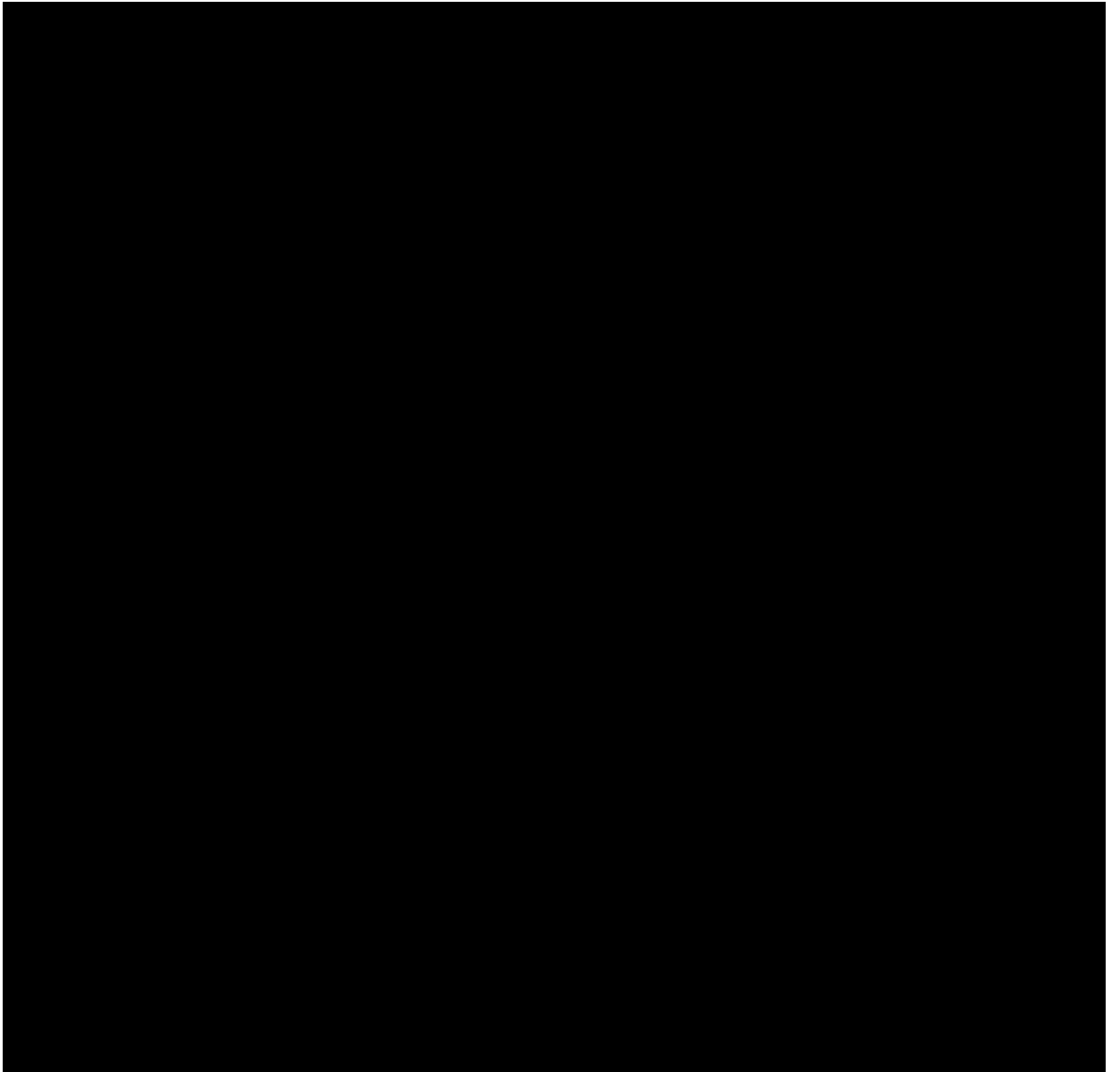












### Appendix 3: Feedback Form

I would be very grateful if you would be able to provide me with some feedback about today's Health Promotion lecture by completing this form as much as possible. *Thank you*

**Please indicate whether you agree/disagree with the following statements.**

		Agree a lot	Agree a little	In between	Disagree a little	Disagree a lot
1)	I was satisfied that the objectives of the lecture were clearly stated at the start of the lecture.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
2)	I felt that today's objectives were met.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
3)	I was satisfied with the lecturer's teaching style.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
4)	I was provided with the opportunity to ask questions that concerned me during the lecture.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
5)	The lecture met my expectations overall.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
6)	I was satisfied with the lecture overall.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

I would appreciate it if you would take some time to reflect on the most/least helpful aspects of the lecture:

a) What were the most/least helpful aspects of the lecture content?

---



---



---

b) What were the most/least helpful aspects of the teaching style throughout this lecture?

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**Thank you**

## Appendix 4: Feedback results

### Feedback Results: Lecture 1 - Health Promotion in Transplantation

		Agree a lot	Agree a little	In between	Disagree a little	Disagree a lot
1)	I was satisfied that the objectives of the lecture were clearly stated at the start of the lecture.	77%	23%	0%	0%	0%
2)	I felt that today's objectives were met.	77%	23%	0%	0%	0%
3)	I was satisfied with the lecturer's teaching style.	82%	18%	0%	0%	0%
4)	I was provided with the opportunity to ask questions that concerned me during the lecture.	95%	5%	0%	0%	0%
5)	The lecture met my expectations overall.	77%	23%	0%	0%	0%
6)	I was satisfied with the lecture overall.	86%	14%	0%	0%	0%

### Feedback Results: Lecture 2 - Health Promotion: Individual-Level Interventions - MSc Health Psych Feedback

		Agree a lot	Agree a little	In between	Disagree a little	Disagree a lot
1)	I was satisfied that the objectives of the lecture were clearly stated at the start of the lecture.	82%	18%	0%	0%	0%
2)	I felt that today's objectives were met.	100%	0%	0%	0%	0%
3)	I was satisfied with the lecturer's teaching style.	64%	27%	9%	0%	0%
4)	I was provided with the opportunity to ask questions that concerned me during the lecture.	100%	0%	0%	0%	0%
5)	The lecture met my expectations overall.	73%	27%	0%	0%	0%
6)	I was satisfied with the lecture overall.	82%	18%	0%	0%	0%

## **Feedback Results: Selection of comments from students**

### **What were the most/least helpful aspects of the lecture content?**

#### *Lecture 1:*

"It was a very interesting lecture, helped me to see how health promotion would work in a real hospital service."

"Gained a real understanding about transplantation. I will put myself on the organ donor list now"

#### *Lecture 2:*

"Most helpful was the information we received during group work. It helped better understand the practical aspects of theory especially since when doing the group session, specific examples were given."

"Most helpful: group work and paper example of RE-AIM"

### **What were the most/least helpful aspects of the teaching style throughout this lecture?**

#### *Lecture 1:*

"Lots of opportunities to ask questions about the topic"

"Shouldn't be expected to answer questions in the lecture. I didn't like that she asked so many"

#### *Lecture 2*

"The lecturer was willing to answer questions and was very good at showing/projecting her knowledge on individual level interventions. At some points it felt like there was too much information coming in! The small group tasks however let us digest the info so that was good"

"We were provided with many opportunities to ask questions. The lecturer was well paced and content was explained clearly."

## Reflective commentary of MSc Health Promotion Lecture

I carried out two lectures on Health Promotion to MSc Health Psychology students. My reflection will be focusing on my first lecture.

After watching the recording I felt that the lecture had gone well. However I observed how feelings of my own frustration came across in my lecture style. I remember feeling unsatisfied by the students' limited knowledge of health promotion models but encouraged by the effort the students made in asking questions and attempting to answer the quiz. Watching it a second time I saw more areas that could have been improved these are highlighted below.

### Body Language – Moving about too much

This indicated how nervous I felt at the time despite appearing confident in the teaching. In previous presentations colleagues noticed how shaky and under-confident I was and how it came through in the lecture. This was an improvement from that time. As the lecture went on I paced about less and appeared more comfortable. At the time, I was aware that I was anxious and worked to slow down my speech; with this my pacing also slowed and I started to feel more comfortable with the situation.

### Teaching Styles and Tools

**Quiz:** I started the lecture with a short quiz. I believed that this would encourage students to interact and speak up in class. It also helped me to gauge the students' knowledge and at what level to target the information. In practice it was maybe too 'directive' in nature and possibly started off with too much pressure on the students. Despite this, they rose to the challenge and although hesitant to start with became more responsive to answering and asking questions and voicing opinions. Some of the quiz questions implied an expectation that the students should know their health promotion models thoroughly and asking questions in this direct manner may have been quite demanding of student participation. On reflection I queried whether I should have been more supportive in nature and nurturing growth and



understanding better by starting the session with a gentler approach and general recap of past lecture material.

**Integrating competition:** At one point I state that half the room were more responsive to questions than the other half of the room. This prompted the next question to be answered by the quieter side of the room. Increasing participation has been noted as one of many strategies that might lead to improved student learning; indeed Stowell and Nelson (2007) found that students with the highest classroom participation also reported greater positive emotion during the lecture. Although there is benefit to this interactive style it can also be unhelpful to students who may be shy or struggle to understand the lecture. A mix of competition, smaller group work and opportunities for students to ask questions individually may provide positive aspects of competition as well as enabling quieter students.

**Pace:** I had initially planned how long to talk on each topic area and each slide and this helped me to keep to the lecture time allocated. I also allowed for some flexibility to answer questions and integrate lots of real life examples. The students brought up some interesting questions around myths and misconceptions of transplantation, being flexible provided time to explore these areas further.

**Personal experiences:** I also asked about student personal experiences. Afterward I wondered if this was too sensitive a topic. In some ways I felt that personal experiences would improve awareness of how Health Psychology topics may impact students' own emotional wellbeing. I have been more aware of this since I have been an Associate Lecturer teaching 3<sup>rd</sup> year psychology students on a unit on Counselling Psychology.

The lecture generated a lot of interest from the students and made them consider not only underlying models but also issues of ethics, cultural issues and real life practice in addition to raising awareness of organ donation amongst the students. However, there was too much didactic teaching and not enough interactive teaching methods. I could have made more use of group work and discussion groups, case studies and practical learning. I took this learning

forward to my second MSc lecture; breaking up short lecture pieces with group exercises and case study material. This method was very well received.

## References

Stowell, J. R., & Nelson, J.M., (2007) Benefits of Electronic Audience Response Systems on Student Participation, Learning, and Emotion. *Teaching of Psychology*. 34(4).

# Teaching and Training Observer Report



**CITY UNIVERSITY  
LONDON**

## **Department of Psychology**

City University  
Northampton Square  
London  
EC1V 0HB

### *Stage 2 Training in Health Psychology/ Doctorate of Psychology*

#### *Teaching and Training Observation Report*

##### **Trainee Details**

Name: Davina Wong  
Chartered Health Psychologist Supervisor: Dr Parmpreet Kalsi  
Audience: MSc Health Psychology students

##### **Please circle the appropriate response and make comments**

Appropriate resources and material were used: Yes  
Delivery of material: Very Good  
Responded effectively to problems, queries and issues during the training: Yes  
Supported students through the learning programme: Yes  
Provided encouragement and accurate feedback to learners during training: Yes  
Appropriate evaluation methods were used: Yes

##### **Comments**

Davina delivered a lecture on individual level health promotion to a group of MSc students. She demonstrated competence in the area of Teaching and Training. She used a range of teaching methods to effectively engage with the students, combining mini didactic presentations and group discussions. She successfully used examples and case-study tasks to help translate the theoretical principles she covered in the lecture.

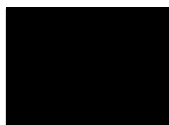
Davina guided the group discussions and was able to successfully return back to the topic when needed. She focused on both individual and population level health promotion actions in the context of renal transplant, as well as a range of health promotion examples (i.e. smoking cessation). She had carefully reviewed the module objectives and obtained relevant information from the module leader to tailor her teaching content, to ensure that she did not overlap with existing teaching. She used a clear and structured approach in designing, delivering and evaluating the teaching session.

She created a safe and respectful environment for students to share their experiences and questions through using appropriate affirmations. Davina demonstrated good verbal and non-verbal communication skills which helped towards building rapport with the audience. She used some interactive tasks to also engage with the group.

##### **Declaration**

I am of the opinion that the above named trainee has completed the teaching and training competence to a high professional standard and is able to act autonomously in this competence.

Signature:



Date: 25/02/14

# TEACHING PROGRAMMES IN HEALTH CARE SETTINGS

## Appendix 1: Motivational Interviewing Teaching Plan

### Strategies to Enhance Motivational Interviewing 20/07/2012

#### Objective:

- To explore an introductory overview of the 'spirit' of MI.
- To provide an alternative framework to work with patients.

**Time:** 1 hour

#### Materials:

- Copies of lecture slides
- Flipchart paper and pens
- Hand outs
- Send round further reading prior to session
- Upload lecture material to renal shared drive

#### Training Needs and Special Requirements for participants

- Basic communication skills to enhance change in 'challenging' patients.
- Introduction to Motivational Interviewing as an alternative framework for working with patients.
- 5-10 participants of varying clinical experience.
- No previous communication skills training.

#### Programme:

##### **15 minutes – Introduction, definitions, open up use of personal experiences**

- What is motivation?

*Basic introduction to motivation and definitions. Initiate thoughts and ideas of what drives and influences individuals to act/change*

- Challenges of motivating change in Chronic Kidney Disease

*Real life experiences and examples from participants. Draw from participant own experience.*

- Looking for motivation in other's

*Draw on participant knowledge, experience and skills.*

- The 'Unmotivated patient'

*Brief information giving. Didactic style.*

##### **20 minutes – Introduce MI as alternative approach, evidence, Spirit of MI**

- Motivational Interviewing: What is it?
- The evidence base
- The Spirit of MI: Collaborative, Evocative, Patient Autonomy

*Brief information giving. Didactic style.*

## **20 minutes – Guiding Principles and Practical skills component of session**

- RULE
- The righting reflex – Helpful Responses Questionnaire
- Communication styles in MI – listening, empowering
- Resistance/Ambivalence
- Change talk

*Mix teaching styles. Include questionnaires. Short task (Helpful Responses) use hand outs if have time.*

### **Further Reading:**

McCarley, P., (2009) Patient Empowerment and Motivational Interviewing: Engaging Patients to Self-Manage Their Own Care. *Nephrology Nursing Journal*. 36(4)

Miller, W.R., & Rollnick, S., (2009) Ten Things that Motivational Interviewing Is Not. *Behavioural and Cognitive Psychotherapy*. 37; 129-140.

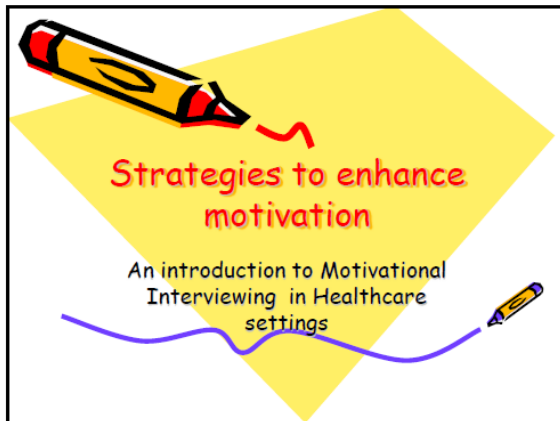
Linden, A., Biuso, T.J., & Butterworth, S.W., (2010) Help Patients with Chronic Kidney Disease stave off dialysis. *The Journal of Family Practice*. 59(4).

Ogedegbe, G., Schoenthaler, A., Richardson, T., Lewis, L., Belue, R., Espinosa, E., Spencer, J., Allegrante, J.P., Chalson, M.E., (2007) An RCT of the effect of Motivational Interviewing on Medicational adherence in Hypertensive African Americans: Rationale and Design. *Contemporary Clinical Trials*. 28: 169-181.

Sevick, M.A., Trauth, J.M., Ling, B.S., Anderson, R.T., Piatt, G.A., Kilbourne, A.M., Goodman, R.M., (2007) Patients with Complex Chronic Diseases: Perspectives on Supporting Self-Management. *Journal of General Internal Medicine*. 22 (3): 438-444.

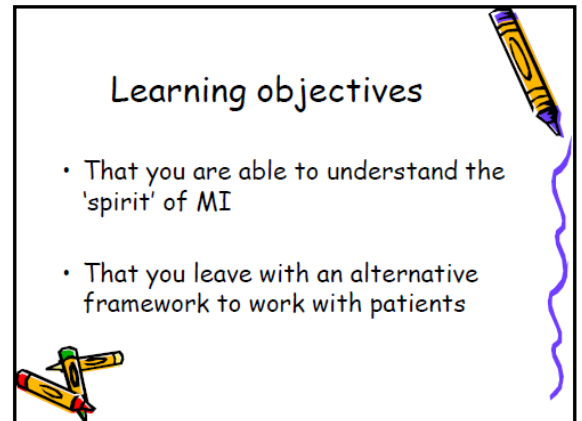
Zuilen, A.D., Wetzels, J.F.M., Bots, M.L., & Blankestijin, P.J., (2008) MASTERPLAN: study of the role of nurse practitioners in a multifactorial intervention to reduce cardiovascular risk in chronic kidney disease patients. *JNephrol*. 21:261-267.

## Appendix 2: Additional Hand Outs Used



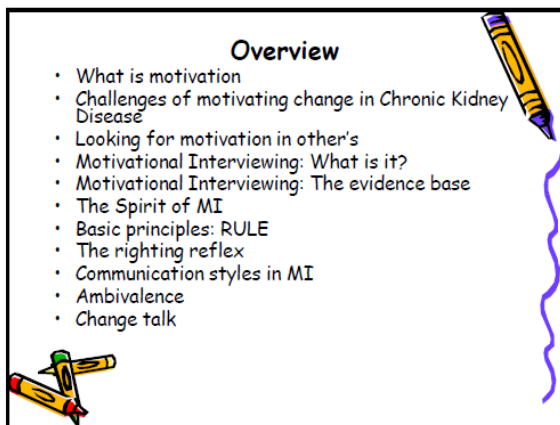
### Strategies to enhance motivation

An introduction to Motivational Interviewing in Healthcare settings



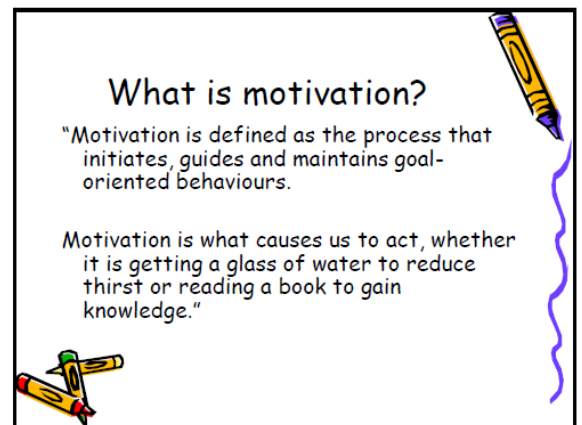
### Learning objectives

- That you are able to understand the 'spirit' of MI
- That you leave with an alternative framework to work with patients



### Overview

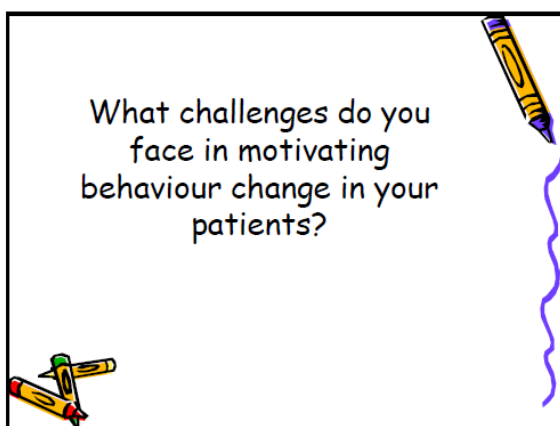
- What is motivation
- Challenges of motivating change in Chronic Kidney Disease
- Looking for motivation in other's
- Motivational Interviewing: What is it?
- Motivational Interviewing: The evidence base
- The Spirit of MI
- Basic principles: RULE
- The righting reflex
- Communication styles in MI
- Ambivalence
- Change talk



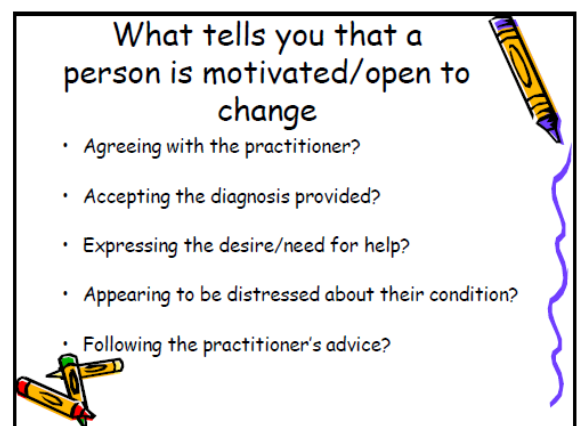
### What is motivation?

"Motivation is defined as the process that initiates, guides and maintains goal-oriented behaviours.

Motivation is what causes us to act, whether it is getting a glass of water to reduce thirst or reading a book to gain knowledge."



### What challenges do you face in motivating behaviour change in your patients?



### What tells you that a person is motivated/open to change

- Agreeing with the practitioner?
- Accepting the diagnosis provided?
- Expressing the desire/need for help?
- Appearing to be distressed about their condition?
- Following the practitioner's advice?

## The problem of the unmotivated patient

"There must be something the matter with this patient and there is not much one can do about it"

e.g.

- They don't see the problem
  - "they must be in denial"
  - "they must lack insight"
- They don't understand the problem
- They don't know how to change
- They don't care

Miller W.R. (2004) Motivational Interviewing in Service to Health Promotion. American Journal of Health Promotion. 18(3)A1-A10

## This usually prompts us to...

- Make them see the problem so they will change (show them some insight)
- Impart wisdom, knowledge and information
- Show them how to do it (teach them to change)
- Make them feel bad or afraid enough for them to change (risk/fear heightening strategy)

No patient is completely unmotivated...

## An alternative perspective

- Inaction is not caused by lack of insight, knowledge, skills or concern
- No change until we resolve patient **AMBIVALENCE**

## Motivational Interviewing: What is it?

"Motivational interviewing is a refined form of the familiar process of guiding"

- It is not a way of tricking people into doing what they don't want to do!
- Resolving ambivalence is central to MI

## Why Motivational Interviewing?

Isn't it for counsellors and psychologists?

- For any health care practitioner who spends time encouraging patients to consider behaviour change.
- Successfully adapted for use in clinic setting.
- There are limits to what a practitioner can do but there is also great potential for change.

Goal: Accessible MI which is learnable; useful and effective in health care practice.

## Motivational Interviewing: The Evidence base

- Clinical method of MI initially developed in 1983 as a brief intervention for problem drinking.
- Miller found that the more counsellors confront clients about their drinking, the more clients drink at follow-up.  
Miller W, Benefield R, Tonigan S. Enhancing motivation for change in problem drinking: a controlled comparison of two therapist styles. J Consult Clin Psychol 1993;61:466-61.
- Client resistance is a product of the interaction with a counsellor who used a confrontational interviewing style.



## Challenges of adapting MI to Healthcare setting

- Dealing with time restraints.
- Client vs Practitioner priorities.
- Multiple problems - setting priorities.



## The "Spirit" of MI

The overall spirit has been described as:

- *Collaborative*
- *Evocative*
- *Honouring patient autonomy*



## Collaborative

- MI rests on the cooperative and collaborative partnership between patient and clinician addressing the specific situation in which patient behaviour change is needed.
- Instead of an uneven power relationship there is an active collaborative conversation and joint decision-making process.



## Evocative

- MI seeks to draw on the patient's own resources.
- Patient may not be motivated to do what you want them to do but they will have personal goals, values, aspirations and dreams.
- The art of MI is connecting health behaviour change with what your patients care about from their own values and concerns.



## Honouring patient autonomy

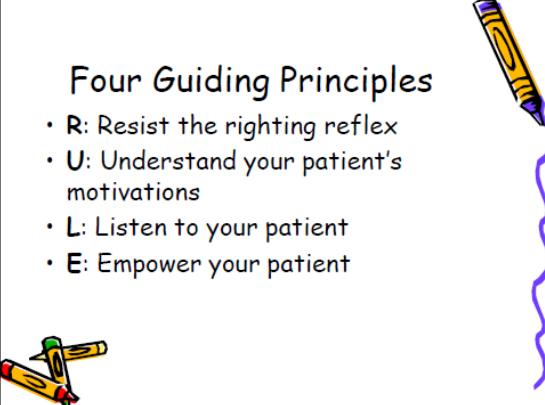
- MI also requires a certain degree of detachment from outcomes.
- Not an absence of caring but an acceptance that people can and do make their own choices about the course of their lives.
- Clinicians can inform, advise and even warn but ultimately it is the patient who decides what to do.
- Sometimes acknowledging the other person's right not to change that makes the change possible.



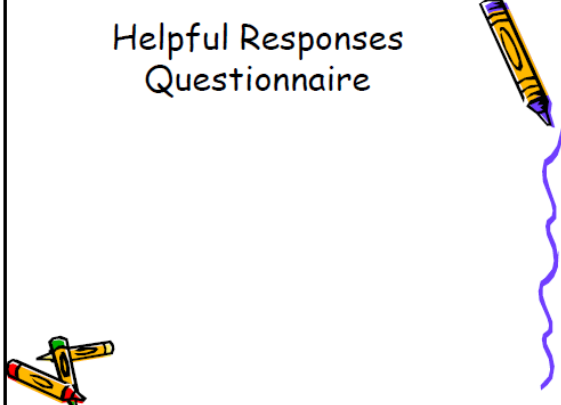


## Four Guiding Principles

- **R**: Resist the righting reflex
- **U**: Understand your patient's motivations
- **L**: Listen to your patient
- **E**: Empower your patient



## Helpful Responses Questionnaire

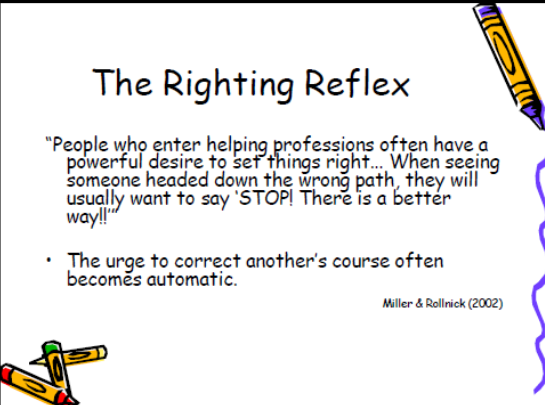


## The Righting Reflex

"People who enter helping professions often have a powerful desire to set things right... When seeing someone headed down the wrong path, they will usually want to say 'STOP! There is a better way!!'"

- The urge to correct another's course often becomes automatic.

Miller & Rollnick (2002)

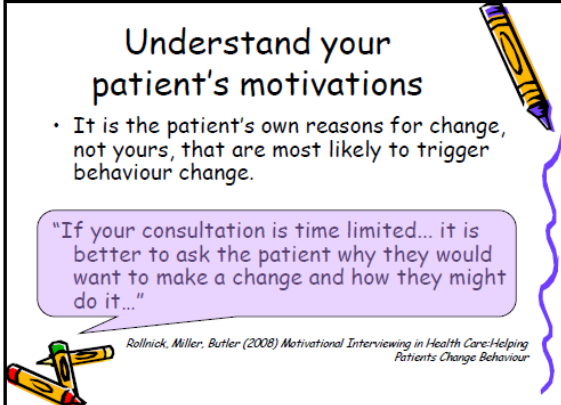


## Understand your patient's motivations

- It is the patient's own reasons for change, not yours, that are most likely to trigger behaviour change.

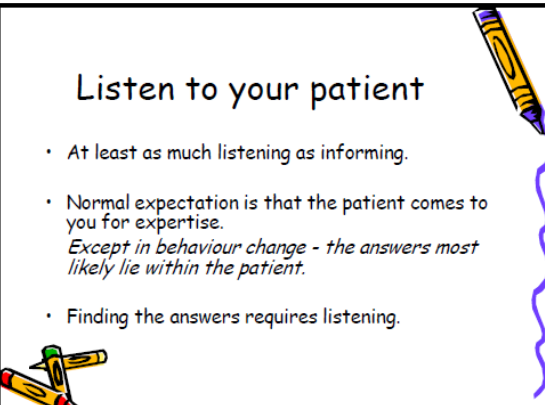
"If your consultation is time limited... it is better to ask the patient why they would want to make a change and how they might do it..."

Rollnick, Miller, Butler (2008) Motivational Interviewing in Health Care-Helping Patients Change Behaviour



## Listen to your patient

- At least as much listening as informing.
- Normal expectation is that the patient comes to you for expertise.  
*Except in behaviour change - the answers most likely lie within the patient.*
- Finding the answers requires listening.

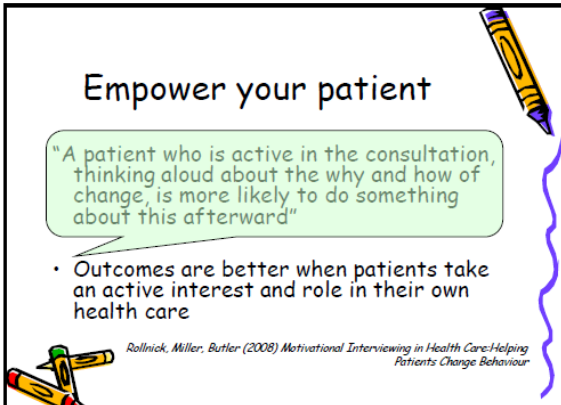


## Empower your patient

"A patient who is active in the consultation, thinking aloud about the why and how of change, is more likely to do something about this afterward"

- Outcomes are better when patients take an active interest and role in their own health care

Rollnick, Miller, Butler (2008) Motivational Interviewing in Health Care-Helping Patients Change Behaviour



## Helpful Responses Questionnaire

- To what extent is your normal style a 'righting reflex' - an attempt to 'fix it'?

## Resistance

- A signal of dissonance and that the person is unlikely to change.

Why does resistance occur?

## Resistance

- Feeling that control has been taken away
- Practitioner jumping ahead of patient's readiness to change
- When force is confronted with force

## Resistance Behaviour

- |                            |   |
|----------------------------|---|
| <b>Arguing:</b>            | Challenging, discounting, hostility   |
| <b>Interrupting:</b>       | Talking over the practitioner   |
| <b>Negating:</b>           | Blaming, disagreeing, excusing, minimising, pessimism, reluctance, unwillingness to change. |
| <b>Ignoring:</b>           | Changing the subject, no response, not paying attention.                                    |
| <b>Passive resistance:</b> | Person just agrees with everything the practitioner says.                                   |

"But I use this every day..."

## 3 Common styles of communication

- Following
  - Asking
  - Informing
  - listening
- Directing
- Guiding

"MI is like dancing rather than wrestling"

## Following

- In the style of *following*, listening dominates.
- Good listening has no agenda to achieve other than seeing and understanding the world through the other's eyes
- In behaviour change *following* communicates "I won't change or push you. I trust your wisdom about yourself"



## Directing

- In this approach You take charge.
- A director tells a person what to do
- In behaviour change *directing* communicates "I know how you can solve this problem. I know what you should do."
- Patients often expect and want this kind of take-charge approach.



## Guiding

- Guiding helps you find your way.
- A good guide knows what is possible and can offer you alternatives from which to choose
- In behaviour change *guiding* communicates "I can help you solve this for yourself"

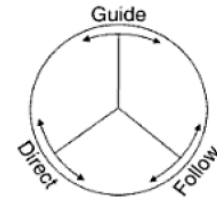


FIGURE 2.1. Three communication styles.

*Rollnick, Miller, Butler (2008) Motivational Interviewing in Health Care-Helping Patients Change Behaviour*



The guiding style of MI works by enhancing patient commitment to change and adherence to treatment

- Why does this happen?



## Ambivalence

- People often feel ambivalent about change
  - Especially change that is 'good' for them!
- People can and do get stuck in ambivalence and they can just enjoy the status quo.
- A telltale sign of ambivalence is the 'BUT'



"I need to lose weight but I hate exercising"

"I want to get up but it hurts"

"I should quit smoking but I just can't seem to do it"

"I mean to take my medicine but I keep forgetting"

Quotes from Rollnick, Miller, Butler (2008) *Motivational Interviewing in Health Care: Helping Patients Change Behaviour*



## Remember 'The Righting Reflex?'

- When a directing style is taken you can often invoke one side of ambivalence



FIGURE 8.1. People can and do become stuck in ambivalence.

- MI says that the common response to these 'pro-change' arguments is to follow your words with 'BUT' in the middle



## Change talk

- Patient is literally talking themselves OUT of change
- Goal for the practitioner using MI is to Elicit Change Talk
  - i.e. want patient to talk themselves into changing



## Key points about MI

- What motivation is.
- Defining Motivational interviewing
  - The Spirit of MI
  - MI's basic principles: RULE
- The righting reflex & resistance.
- Communication styles: Following, Directing Guiding.
- Looking out for Ambivalence is key
- Eliciting change talk



## Helpful Responses Questionnaire

Miller, W. R., Hedrick, K. E., & Orlofsky, D. (1991). The Helpful Responses Questionnaire: A procedure for measuring therapeutic empathy. *Journal of Clinical Psychology, 47*, 444-448.

The following six paragraphs are things that a person might say to you. With each paragraph, imagine that someone you know is talking to you and explaining a problem that he or she is having. You want to help by saying the right thing. Think about each paragraph. On a separate sheet of paper write, for each paragraph, the *next thing* you might say if you wanted to be helpful. Write only one or two sentences for each situation.

**1. A forty-one-year-old woman says:**

*"Last night Joe really got high and he came home late and we had a big fight. He yelled at me and I yelled back and then he hit me hard! He broke a window and the TV set, too!*

*It was like he was crazy. I just don't know what to do!"*

**2. A thirty-six-year-old man says:**

*"My neighbor really makes me mad. He's always over here bothering us or borrowing things that he never returns. Sometimes he calls us late at night after we've gone to bed and I really feel like telling him to get lost."*

**3. A fifteen-year-old girl says:**

*"I'm really mixed up. A lot of my friends, they stay out real late and do things their parents don't know about. They always want me to come along and I don't want them to think I'm weird or something, but I don't know what would happen if I went along either."*

**4. A thirty-five-year-old parent says:**

*"My Maria is a good girl. She's never been in trouble, but I worry about her. Lately she wants to stay out later and later and sometimes I don't know where she is. She just had her ears pierced without asking me! And some of the friends she brings home--well, I've told her again and again to stay away from that kind. They're no good for her, but she won't listen."*

**5. A forty-three-year-old man says:**

*"I really feel awful. Last night I got drunk and I don't even remember what I did. This morning I found out that the screen of the television is busted and I think I probably did it, but my wife isn't even talking to me. I don't think I'm an alcoholic, you know, 'cause I can go for weeks without drinking. But this has got to change."*

**6. A fifty-nine-year-old unemployed teacher says:**

*"My life just doesn't seem worth living any more. I'm a lousy father. I can't get a job. Nothing good ever happens to me. Everything I try to do turns rotten. Sometimes I wonder whether it's worth it."*

### Six Kinds of Change Talk

- **Desire** Statements about preference for change.  
“I *want* to...”  
“I *would like* to...”  
“I *wish*...”
- **Ability** Statements about preference for change  
“I *could*...”  
“I *can*...”  
“I might be able to...”
- **Reasons** Specific Arguments for change  
“I would probably feel better if I...”  
“I need to have more energy to play with my kids.”
- **Needs** Statements about feeling obliged to change  
“I *ought* to...”  
“I *have* to...”  
“I really *should*...”
- **Commitments** Statements about the likelihood of change  
“I am *going* to...”  
“I *will*...”  
“I *intend* to...”
- **Taking steps** Statements about action taken  
“I actually went out and...”  
“This week I started

## **Twelve Roadblocks to Listening**

*(Thomas Gordon, Ph.D.)*

1. Ordering, directing, or commanding
2. Warning or threatening
3. Giving advice, making suggestions, or providing solutions
4. Persuading with logic, arguing, or lecturing
5. Moralizing, preaching, or telling clients what they "should" do
6. Disagreeing, judging, criticizing, or blaming
7. Agreeing, approving, or praising
8. Shaming, ridiculing, or labeling
9. Interpreting or analyzing
10. Reassuring, sympathizing, or consoling
11. Questioning or probing
12. Withdrawing, distracting, humoring, or changing the subject

### Appendix 3: Evaluation Form

#### Strategies to enhance motivation: An Introduction to Motivational Interviewing in Healthcare settings

**Your objective feedback would be greatly appreciated.**

Please answer all the statements according to the following 1 to 5 scale:-  
 1 = Strongly Disagree (SD), 2 = Disagree (D), 3 = Neutral (N), 4 = Agree (A) and  
 5 = Strongly Agree (SA)

Please **tick a number** between 1 and 5 to indicate which response best fits your experience of the session.

		SD	D	N	A	SA
<b>CONTENT</b>						
	The content was at an appropriate level	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
	The content was relevant	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
<b>STRUCTURE</b>						
	There was a clear introduction to the subject	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
	The aims and objectives were clearly stated	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
	The material was well organised	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
	There was a clear summary and conclusion	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
<b>PRESENTATION</b>						
	The presenter appeared well informed about the subject	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
	The presenter appeared enthusiastic about the subject	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
	Audience participation and interaction was encouraged	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
	There was effective use of audio visual aids/handouts	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
	The presentation was given at the right pace	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
	The presentation was of a reasonable length	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
<b>OVERALL</b>						
	Overall, this session was of a high quality	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

I **liked** the following things about the session:

The session might be **improved** by:

I would like a follow up session on developing Motivational Interviewing skills

I would like a repeated session later in the year (as a reminder/recap)



Please return your completed feedback form via email to [REDACTED] or print out and leave in the Psychology in tray on the upper 3<sup>rd</sup> floor for anonymity.

***Thank you!!!!***

## Evaluation Form Results

1 = Strongly Disagree (SD), 2 = Disagree (D), 3 = Neutral (N), 4 = Agree (A) and 5 = Strongly Agree (SA)

		SD	D	N	A	SA
<b>CONTENT</b>						
	The content was at an appropriate level	0%	0%	0%	100%	0%
	The content was relevant	0%	0%	0%	100%	0%
<i>All attendees "Agreed" that the content was at an appropriate level and relevant.</i>						
<b>STRUCTURE</b>						
	There was a clear introduction to the subject	0%	0%	0%	100%	0%
	The aims and objectives were clearly stated	0%	0%	0%	66%	33%
	The material was well organised	0%	0%	0%	100%	0%
	There was a clear summary and conclusion	0%	0%	0%	100%	0%
<i>All attendees "Agreed" or "Strongly Agreed" that the structure was clear, objectives met, materials were well organised with clear summaries and conclusions.</i>						
<b>PRESENTATION</b>						
	The presenter appeared well informed about the subject	0%	0%	0%	66%	33%
	The presenter appeared enthusiastic about the subject	0%	0%	0%	100%	0%
	Audience participation and interaction was encouraged	0%	0%	0%	100%	0%
	There was effective use of audio visual aids/handouts	0%	0%	0%	100%	0%
	The presentation was given at the right pace	0%	0%	0%	100%	0%
	The presentation was of a reasonable length	0%	0%	0%	100%	0%
<i>All attendees "Agreed" or "Strongly Agreed" that the presenter was well informed, enthusiastic and encouraging, participatory and interactive. Used hand outs and audio visual aids effectively and presented as a good pace.</i>						
<b>OVERALL</b>						
	Overall, this session was of a high quality	0%	0%	0%	66%	33%
Overall feedback was very good with no negative comments.						

I **liked** the following things about the session:

*"It was informative and not overwhelming would like 2<sup>nd</sup> part or follow up with extra info".*

*"One Hour was enough to give as a taster session and gave us a sense of Spirit of MI."*

The session might be **improved** by:

*"If we had more time to go through specific techniques that we needed to skip through quickly"*

I would like a follow up session on developing Motivational Interviewing skills **100%**

I would like a repeated session later in the year (as a reminder/recap) **66%**

# **APPENDICES: CORE UNIT**

## **5**

### **Behaviour Change**

## Appendix 1: Referral guidelines



### Renal Clinical Health Psychology Service

#### Information and Guidelines for Referrers

The service is provided by two HPC registered\* psychologists and one assistant psychologist, providing sessions at the Royal Free Hospital (to Low Clearance & Transplant) and to four satellite haemodialysis units (RDU, MRU, Barnet and N. Middx). Alternatives to direct referral, include consultation and advice on patient management, teaching psychological skills to staff and providing clinical supervision.

#### Main Areas of Involvement

- The assessment of, and support for psychological distress associated with medical illness or medical interventions.
- Assisting the self-management of chronic medical conditions and prevention of further disease or deterioration.
- The promotion of better functioning by increasing the patient's understanding of self and their reactions to illness and/or medical settings.
- Promotion and maintenance of healthy behaviours through Psycho-education and skills training.
- Dissemination of psychological knowledge to enhance other health care staff's understanding and management of patient's response to illness or treatment.
- Advice on local and referral to regional therapy services for those whose difficulties are unrelated to their renal disease and/or for whom a more specialist service is appropriate.

#### Examples of appropriate referrals:

- Patients having prolonged difficulty making transitions, (e.g. to dialysis, and to changes in health)
- Patients suffering severe or acute psychological disturbance **as a result** of their medical condition (e.g. reactive clinical depression or anxiety that has not resolved over a normal period of adjustment).
- Patients with adverse psychological reactions in response to their impending or completed medical treatment (e.g. needle phobia, anticipatory sickness, post traumatic stress reaction, severe difficulty adjusting to diagnosis).
- Patients failing to adhere to important aspects of their medical treatment (e.g. failing to take anti-rejection drugs)

#### Examples of unsuitable referrals:

- Patients who show a normal reaction such as emotional distress to a potentially distressing common life event (e.g. bereavement - unless their reaction is very severe or prolonged and interferes with their medical management)
- Patients with pre-existing mental health problems - who should be referred to community services.
- Patient facing normal but unwanted life events
- Patients with psycho-social problems not connected to their illness (e.g. pre-existing marital problems).
- Patients whose challenging behaviour stems from an underlying longstanding personality disorder, not responsive to brief or short term psychological therapy (advice can be given on specialist treatment centres)

**The service is not appropriate for crisis or emergency psychiatric patients who are more appropriately referred to local psychiatric teams, crisis interventions services, A&E or to their GP's.**

#### How to refer

Please contact Dr Jeff Cove, Consultant Clinical Psychologist or Dr Sarah Afuwape, Highly Specialist Applied Health Psychologist, if you would like to discuss a potential referral prior to sending a referral letter to the address given below. **Obtain the patient's consent prior to making the referral** and make clear any special requirements such as language needs or transport. The referral letter should include a description of the problem and relevant background history.

Email addresses: [rfh-tr.RFH-RenalPsychology@nhs.net](mailto:rfh-tr.RFH-RenalPsychology@nhs.net)

Tel: 020 7794 0500 ext 37571 (9.30-5.30pm answering machine available for out of hours)

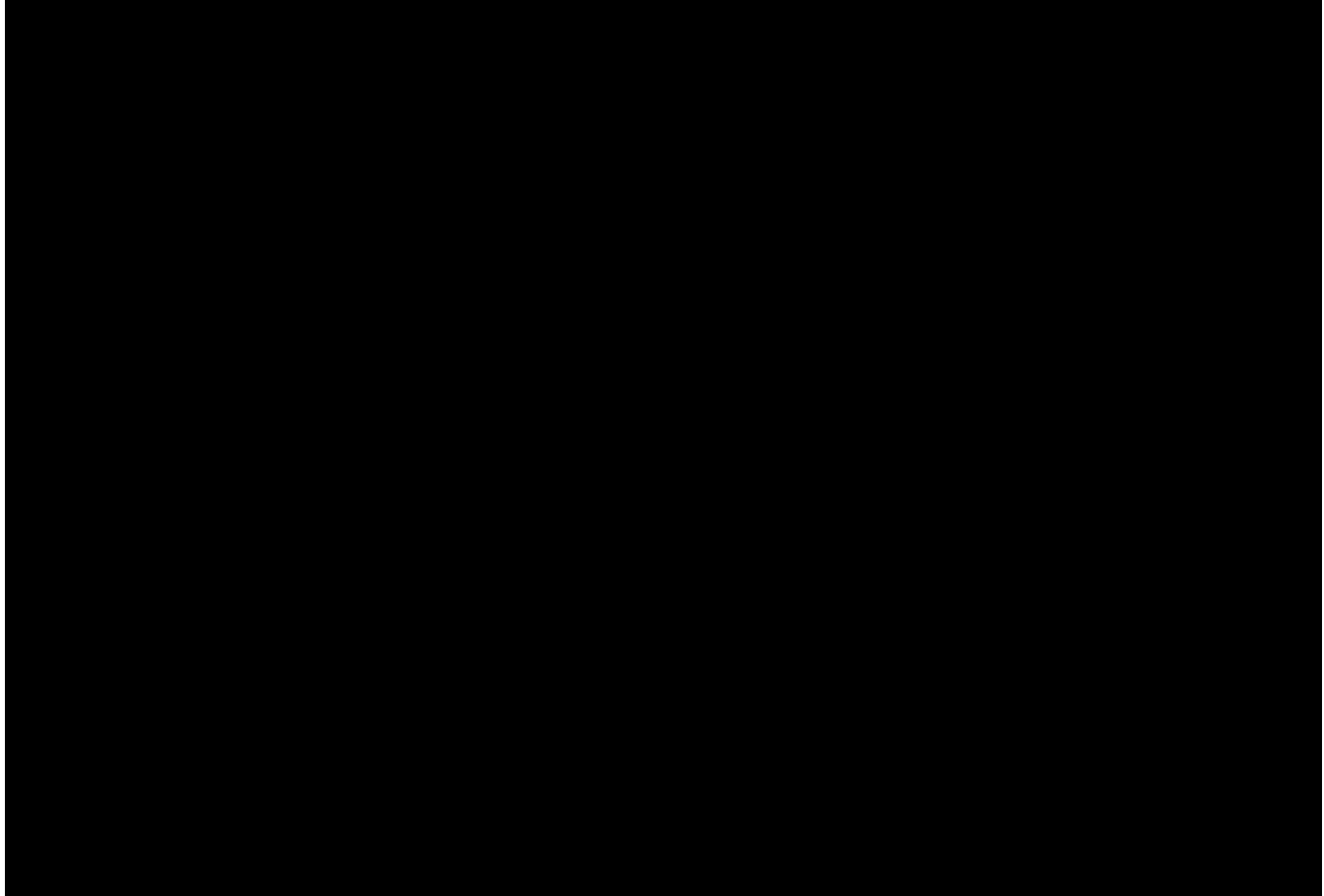
Address: **Renal Clinical Health Psychology, Upper 3<sup>rd</sup> Floor, Royal Free Hospital, NW3 2QG**

\*Health Professions Council (HPC) registered

## Appendix 2: Referral Algorithm

### Renal Clinical Health Psychology

#### Referral Algorithm



## Appendix 3: Patient information leaflet

### Confidentiality

Any notes that the psychologist takes during or after your appointments will be kept separate from your medical records and stored securely and confidentially.

The psychologist may want to share some of the issues discussed with your renal care team, as it may help them improve your care. The person who referred you will also be informed that you have been seen by a psychologist.

Anything that you want to remain confidential will be respected wherever possible, subject to the need to consider the safety of yourself and others.

### How can I contact you / be referred?

- If you have been referred and need to contact us before your appointment please follow the instructions in your appointment letter.
- If you would like to be referred to the renal clinical health psychology service you can request to be referred by one of the renal care team members ie. your doctor, nurse, social worker, or dietician.

### For further information:

- [www.kidneypatientguide.org.uk](http://www.kidneypatientguide.org.uk)
- [www.kidney.org.uk](http://www.kidney.org.uk)
- [www.kidney.org](http://www.kidney.org)
- [www.kidneyschool.org](http://www.kidneyschool.org)
- [www.homedialysis.org](http://www.homedialysis.org)
- British Association of Counselling  
Tel. 01788 578328
- Relate [www.relate.org](http://www.relate.org)  
Tel. 01788 573241
- MIND [www.mind.org.uk](http://www.mind.org.uk)
- Camden & Islington Mental Health Services [www.candi.nhs.uk](http://www.candi.nhs.uk)  
Tel. 020 7685 4700

**ROYALFREE**  
world class care and expertise

## Renal clinical health psychology service

Information for patients with renal disease referred for psychological support



If you would like a large print or audio version of this information, please ask a member of staff.

© Renal clinical health psychology / Patient information programme 2010  
[review date: April 2012]  
[www.royalfree.nhs.uk](http://www.royalfree.nhs.uk)

Royal Free Hampstead **NHS**  
Trust

### What is renal psychology?

We specialise in helping people cope with and adjust to emotional stresses and strains that can happen when they have physical health problems. We are not medical doctors so we do not prescribe any medication and are primarily a brief therapy service. However we can work with people who have emotional and psychological problems related to their renal disease, or even help you to cope with symptoms related to renal disease.

The renal clinical health psychology service consists of clinical psychologists, health psychologists and counselling psychologists.

### Why might I be referred / Why might I want to see a psychologist?

Kidney disease can have a major impact on someone's life. It is normal to experience a range of emotions and to sometimes feel unable to cope. It is also common to have worries about your health, be angry about your situation or feel overwhelmed with your problems. Speaking to a psychologist provides an opportunity for you to discuss some of these issues. You may have been referred to the renal psychology team for a variety of reasons such as:

- To discuss issues such as accepting a diagnosis
- To address lifestyle changes that may be required eg. how to incorporate a complicated medical regime into your lifestyle
- Stress factors, anxiety or mood problems that can affect how you deal with kidney disease

**Transplant assessments:** You may also have been referred to the renal psychology team, for an assessment as part of your 'work up' for transplant (A wide range of information is necessary to determine eligibility for transplant including several medical tests and doctor appointments. This is what a 'work up' consists of). A psychological assessment is an important part of the pre-transplant process, which also assesses your suitability for transplant. You can discuss issues relating to preparing for transplant, your expectations and your understanding of the transplant, as well as life after transplant.

### What if I do not want to see a psychologist?

Although one of your renal care team may have suggested that you might benefit from seeing a psychologist, you can choose not to and it will not affect any other aspect of your care.

- A referral to the psychologist should be discussed and agreed with you by one of the renal team before it is made.
- Pre-transplant psychology assessments are part of the protocol for your 'work up'. If you have consented to the work up, you will have also consented to a pre-transplant assessment with a psychologist

### Your first appointment

Your first meeting with the psychologist will be an informal discussion, which will last about an hour.

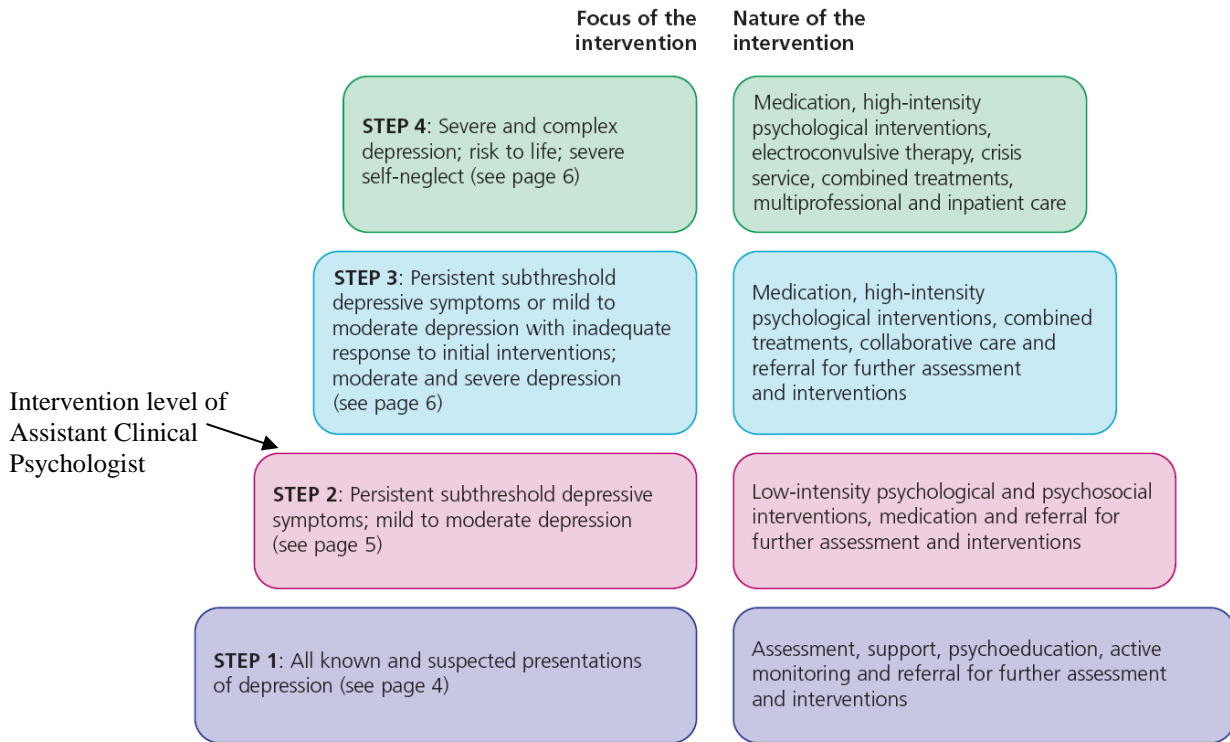
The psychologist will ask you some background details, and you may be asked to complete a short questionnaire.

In the rest of the appointment you can discuss issues concerning you, and you can decide with the psychologist what support from the service would be most helpful. You may decide not to take up any further appointments, or be referred on to another service. However you will be able to request another appointment at any time in the future.

## Appendix 4: Stepped Care Model

### The stepped-care model

This model provides a framework for organising the provision of services, and helps patients, carers and practitioners to identify and access the most effective interventions. The least intrusive, most effective intervention is provided first. If a person does not benefit from that intervention, or declines an intervention, they should be offered an appropriate intervention from the next step.



NICE Clinical Guideline 91: Depression in adults with a chronic physical health problem - Treatment and management (2009)

## Appendix 5: Stages of CKD

Stage	Description	GFR* mL/min/1.73m <sup>2</sup>
1	Slight kidney damage with normal or increased filtration	More than 90
2	Mild decrease in kidney function	60-89
3	Moderate decrease in kidney function	30-59
4	Severe decrease in kidney function	15-29
5	Kidney failure	Less than 15 (or dialysis)

\*GFR is glomerular filtration rate, a measure of the kidney's function.

At this stage patients are seen in 'Low Clearance Clinics'



## Appendix 6: Summary of guided CBT

### Introduction:

The provision of Guided or Low Intensity Cognitive Behavioural Therapy (CBT) was based on government commitments to improve the availability of psychological therapies particularly relating to people with depression and/or anxiety. The National Institute for Health and Clinical Excellence recommended Cognitive Behavioural Therapy as an effective treatment within the NHS. CBT is offered in the form of the 'Stepped Care Model' (see Appendix 4: 'The Stepped Care Model') within which a range of professionals are trained in two specific levels of CBT; Low intensity CBT (or Guided CBT) and High intensity CBT.

### What is CBT?:

CBT was developed from the idea that individuals' feelings can be related to their thoughts and behaviour. Therefore by discussing how one thinks, and what one does CBT can help an individual change the way they think ('cognitive') and what they do ('behaviour'), which can help their feelings change too.

### Clinical effectiveness of low-intensity CBT:

Low intensity CBT allows the same theoretical and empirically valid treatment to be delivered as High intensity CBT, but in a different format. Whereas high intensity treatment involves a considerable amount of therapist input, low intensity treatments emphasises patient self-management through the use of clinical resources such as guided self-help, reducing patient-clinician contact time. Turpin, Richards, Hope and Duffy (2008) report that the effect size for low intensity CBT for depression is similar to the effect size reported for high intensity CBT (0.8). However, low intensity CBT is more variably affective for anxiety disorders (range 0.18-1.02). This emphasises the importance of the 'Stepped Care model' in which a patient being seen for low intensity CBT can be 'stepped up' to high intensity CBT if guided self-help and self-management techniques are not effective.

### Reference:

- Turpin, G., Richards, D., Hope, R., Duffy, R. (2008) The IAPT programme. Retrieved 21 March 2011 from [http://www.bps.org.uk/dcp/iapt/iapt\\_cbt\\_publications.cfm](http://www.bps.org.uk/dcp/iapt/iapt_cbt_publications.cfm)

## Appendix 7: Summary and Use of Brief Solution Focused Therapy

### Background and Effectiveness:

Brief Solution Focused Therapy (BSFT) was developed at the Brief Family Therapy Center (de Shazer, 1988, 1994 and Berg, 1991; Berg & Miller 1992). It is an approach to psychotherapy which is based on solution building instead of problem solving. Its techniques explore an individuals current resources and future hopes rather than focusing on their presenting problem. Since its origins, BSFT has proven to be an effective intervention across a range of presenting problems (de Shazer, 1988; Miller et al, 1996; Hawkes et al, 1998; Rhodes & Ajmal, 1995; O'Connell, 1998; Sharry, 2001).

### Skills and Components of Brief Solution Focused Therapy used with XX:

#### Defining Goals and Visualising a Preferred Future – The Miracle Question

The Miracle question is a method of amplifying what the patient wants. It is essentially a method to help patients explore how they would like their life to be like and start defining goals. Additionally it puts goals in a realistic context. The way the miracle question is approached can help patients visualise a reality where their problem is no longer a problem.

That miracle question is a useful tool for a number of reasons. First through asking about a miracle, it gives patients permission to think creatively about an unlimited range of possibilities. Patients are asked to think 'big' as a way to start identifying what changes they would like to see and what goals might be useful to focus on for therapy. Second the question is framed so that it has a future focus allowing the patient to move away from their current and past problems and toward a more satisfying future (De Jong & Berg, 2002).

### Scaling

A useful framework for BSFT is the use of 0 to 10 scales, where 10 is the achievement of all the goals and zero is the worst possible scenario. The individual is asked to identify their current position and at which point they would be sufficiently satisfied. Scaling can be used to differentiate different problem areas and focus on the solutions. However it is also a useful tool to help both individual and clinician monitor and measure progress and patient expectations (See Figure 1 below).

<i>Points to mark</i>	<i>What to explore</i>
10 – The perfect solution	The miracle question as a means to encourage creative thinking
7 – A good but realistic outcome	A realistic description of the client getting on with his/her life without the problem interfering too much. The more concrete and realistic the better, since it is the small, mundane aspects of living that go together to make a good-enough life
3 – Where the client is now	Everything the client is doing that has helped him or her reach this point on the scale and/or everything he/she is doing to prevent matters getting worse
0 – The worst scenario	Best not to go into detail

Figure 1 The Scale Framework, Iveson (2002)

### Coping, Exceptions and Compliments

A running theme throughout BSFT is for the clinician to search and question the individual for their strengths and resources, consistently commenting on them. Curiosity about how the individual copes and looking for exceptions can draw attention to the fact that they do cope and manage in their daily lives with the problem already.

### References

- De Jong, P. & Berg, I.K. (2002) Interviewing for Solutions. 2<sup>nd</sup> Ed. Brooks/Cole.
- Iveson, C. (2002) Solution-Focused Brief Therapy. Advances in Psychiatric Treatment. 8, 149-157.

## Appendix 8: Referral Form



### Patient Referral Form for Renal Clinical Health Psychology Service

Please complete as much information as possible. Please complete all areas labelled with a \*.

<b>*Part One: Patient's details</b>			
*Patient Name: ■■■■	*Date of birth :	*Male <input type="checkbox"/> Female <input checked="" type="checkbox"/>	
*RF No:	*Patients preferred contact numbers:	or	
May we leave a message? Yes <input checked="" type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/>	Re-referral? <input checked="" type="checkbox"/> (tick for yes)		
*Is the client in agreement with the referral? Yes <input checked="" type="checkbox"/> No <input type="checkbox"/> Primary Care Trust:			
*If Interpreter required which language?		Requires Hospital Transport? Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>	
<b>*Part Two: Clinical details</b> *Patient currently under which service?			
Low Clearance <input type="checkbox"/> Haemodialysis <input type="checkbox"/> Pre-Transplant Clinic <input type="checkbox"/> Post Transplant Clinic <input type="checkbox"/> Peritoneal Dialysis <input checked="" type="checkbox"/> Home Haemodialysis <input type="checkbox"/> Donor <input type="checkbox"/> Other (please state)			
Main Location where patient receives their renal care? (RF, MRU, NMH etc) RFH			
Is this person an inpatient? <input type="checkbox"/> State ward			
<b>*Part Three : Patient's Problem</b>			
*Is this problem significantly impacting on person's renal care? Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>			
<b>Reason for referral (tick as many as apply)</b>			
Transplant Assessments: Recipient Assessment <input type="checkbox"/> Live Donor Assessment <input type="checkbox"/> Altruistic Assessment <input type="checkbox"/>	Adherence <input checked="" type="checkbox"/>	Depression (low mood) <input checked="" type="checkbox"/>	Relationship problems <input type="checkbox"/>
	Coping <input type="checkbox"/>	Anxiety <input checked="" type="checkbox"/>	Sleep problems <input checked="" type="checkbox"/>
	Treatment Choices <input type="checkbox"/>	Adjustment <input checked="" type="checkbox"/>	Weight management <input type="checkbox"/>
	Grievances <input type="checkbox"/>	Bereavement <input type="checkbox"/>	Home Haemo Assmt <input type="checkbox"/>
Other (please state)			
<b>Other useful information to support referral</b>			
PD at home, alarms go off at night preventing good night sleep. Low mood, loss of appetite. Sometimes avoids dialysis.			
<b>*Part Four : Referrer's details</b>			
*Name:	Job title: Clinical Nurse Specialist	Bleep no/telephone extrn:	
*Location: RFH	*Date : 20/09/2010		
<b>Office Use</b>			
Referral received by:	Date:	Allocated to:	Date:
Date previously referred (if re-referral):			
Database updated: at start of case <input type="checkbox"/> at close of case <input type="checkbox"/>			
Date first appt invite letter sent _____	Date first appt given _____	Attended <input type="checkbox"/>	DNA'd <input type="checkbox"/> Rearranged <input type="checkbox"/> _____
Date second appt invite letter sent _____	Date second appt given _____	Attended <input type="checkbox"/>	DNA'd <input type="checkbox"/> Rearranged <input type="checkbox"/> _____ N/A <input type="checkbox"/>
If two DNA's: date discharge letter sent _____			
Assessment Date _____			
Number of sessions offered: _____		Number of sessions DNA'd: _____ Number of sessions attended: _____	
Date case closed _____		Date update sent to referrer _____	

**Please return this referral form to:**  
**Renal Clinical Health Psychology Service, Upper 3<sup>rd</sup> Floor, Royal Free Hospital, NW3 2QG. Tel: 02077940500 ext 37571, Email: [rfh-tr.RFH-RenalPsychology@nhs.net](mailto:rfh-tr.RFH-RenalPsychology@nhs.net), Fax: 02078302125 (if faxing from external site) 35988 (if faxing from RF internal site). Please call Renal Psychology after faxing to acknowledge receipt of referral.**

## Appendix 9: Hospital Anxiety and Depression Scale<sup>2</sup>

### Hospital Anxiety and Depression Score (HADS)

This questionnaire helps your physician to know how you are feeling. Read every sentence. Place an "X" on the answer that best describes how you have been feeling during the LAST WEEK. You do not have to think too much to answer. In this questionnaire, spontaneous answers are more important

<b>A</b>	I feel tense or 'wound up':	
	Most of the time	3
	A lot of the time	2
	From time to time (occ.)	1
	Not at all	0
<b>D</b>	I still enjoy the things I used to enjoy:	
	Definitely as much	0
	Not quite as much	1
	Only a little	2
	Hardly at all	3
<b>A</b>	I get a sort of frightened feeling as if something awful is about to happen:	
	Very definitely and quite badly	3
	Yes, but not too badly	2
	A little, but it doesn't worry me	1
	Not at all	0
<b>D</b>	I can laugh and see the funny side of things:	
	As much as I always could	0
	Not quite so much now	1
	Definitely not so much now	2
	Not at all	3
<b>A</b>	Worrying thoughts go through my mind:	
	A great deal of the time	3
	A lot of the time	2
	From time to time, but not often	1
	Only occasionally	0
<b>D</b>	I feel cheerful:	
	Not at all	3
	Not often	2
	Sometimes	1
	Most of the time	0
<b>A</b>	I can sit at ease and feel relaxed:	
	Definitely	0
	Usually	1
	Not often	2
	Not at all	3

<b>D</b>	I feel as if I am slowed down:	
	Nearly all the time	3
	Very often	2
	Sometimes	1
	Not at all	0
<b>A</b>	I get a sort of frightened feeling like "butterflies" in the stomach:	
	Not at all	0
	Occasionally	1
	Quite often	2
	Very often	3
<b>D</b>	I have lost interest in my appearance:	
	Definitely	3
	I don't take as much care as I should	2
	I may not take quite as much care	1
	I take just as much care	0
<b>A</b>	I feel restless as I have to be on the move:	
	Very much indeed	3
	Quite a lot	2
	Not very much	1
	Not at all	0
<b>D</b>	I look forward with enjoyment to things:	
	As much as I ever did	0
	Rather less than I used to	1
	Definitely less than I used to	2
	Hardly at all	3
<b>A</b>	I get sudden feelings of panic:	
	Very often indeed	3
	Quite often	2
	Not very often	1
	Not at all	0
<b>D</b>	I can enjoy a good book or radio/TV program:	
	Often	0
	Sometimes	1
	Not often	2
	Very seldom	3

<sup>2</sup> Licensed version used for Case Study

# **APPENDICES: CORE UNIT**

## **6.3**

### **COMMUNICATE PROCESS**

### **AND OUTCOMES OF**

### **INTERVENTION OR**

### **CONSULTANCY**

## Appendix 1: Mind and Body Matters Abstract



Solihull. 6/7th November 2011

READ ALL THE INSTRUCTIONS ON ACCOMPANYING FORM CAREFULLY BEFORE YOU BEGIN YOUR ABSTRACT. ABSTRACTS CAN EITHER BE TYPED ON THIS FORM AND POSTED, OR SAVED TO YOUR PC. AND EMAILED TO THE KEY MEMBER.

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### ABSTRACT TITLE

**Mind and Body Matters in Renal Care**

### ABSTRACT TEXT

**Background:** Patients who are able to incorporate self-management into their daily living feel better informed and more actively involved in making treatment decisions. Understanding of their medical condition is also a significant predictor of treatment adherence. Psycho-education is a model in which education is offered to individuals with physical illnesses. ‘Mind and Body Matters in Renal Care’ was developed as a ‘passive psycho-educational’ pilot project for patients in the transition period of approaching renal replacement therapy. A ‘passive psycho-educational’ approach is a method of providing information, education materials and/or advice. ‘Preparation’, ‘cognitive style’ and ‘social support’ are key concepts in supporting patients during transition periods and ‘Mind and Body Matters’ aimed to capitalise on these concepts.

**Objectives:** The aim of the project was to help patients who are in the transition period from diagnosis to end stage renal disease to cope with their condition through general education about their illness and the advantages of enhancing their psychological and physical self-management.

**Methodology:** Two hundred patients referred to the Low Clearance Clinics over a period of 8 months (from 1<sup>st</sup> October 2010 to 31<sup>st</sup> May 2011) were invited by letter to ‘Mind and Body Matters in Renal Care’ workshops. The workshops were split into two sessions and included a brief presentation, discussions and activities with an interactive approach. Both sessions were run by specialist psychologists and supported by a Low Clearance nurse. The first session focused on ‘*adjusting to renal problems*’, including a review of patients’ knowledge of renal disease; coming to terms with diagnosis; and adherence issues. The second session focused on ‘*skills for managing stress and developing coping strategies*’ aimed to help patients identify symptoms of stress, anxiety and depression. It included practical stress management strategies, self-care and communication with health care professionals.

Groups were limited to 12-15 people per workshop, and relatives and carers were encouraged to attend. In order to assess patients’ knowledge and confidence in self-management, participants completed a questionnaire before and after the sessions.

**Findings:** Thirty five patients opted to attend the workshops, with an additional 25 relatives/friends. Overall, patients perceived they had fairly good knowledge prior to both session 1 and 2, stating 'very good' or 'quite good' knowledge/understanding of kidney disease, adherence to treatment regimen, coping and a good understanding of stress, anxiety and low mood. However after attending, the participants stated a further knowledge gain from both workshops. Participants initially noted lower self-motivation and confidence to make changes in their lifestyle, but felt more motivated and confident at the end of the workshops. Practical stress management strategies, such as sleep management and relaxation, were highlighted as particularly useful and participants also felt more confident in communicating their concerns in medical settings.

Verbal and written feedback from participants showed that the structure of the workshops were most helpful, allowing patients to attend with relatives or friends. The small groups and open discussion format enabled participants to raise individual concerns to share with the group. Limitations concerned access; some patients who wanted to attend were unable to due to living far away, lack of mobility and hospital transport restrictions. Workshops are ongoing and continue to gain patient interest.

**Conclusion:** Initial results indicate that the workshops are highly valued by patients. Of particular interest is patient perception that they already have good knowledge regarding self-management strategies prior to starting the workshop, but lower self motivation and confidence to make changes in their lifestyle. The workshops proved useful in addressing this and helping patients increase their knowledge, motivation and confidence in self-management. Increasing participant uptake and access to the groups needs to be addressed in future workshops.

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The work in this paper is original  yes /  No First named author is primary researcher  yes /  No

This abstract has been presented / submitted elsewhere  yes /  No – if yes, state location and date:

.....  
I confirm that this abstract contains information and results that have been completed and reflects a true and accurate status of the results of work completed at this time. I hereby assign copyright of this abstract to EDTNA/ERCA.

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## Appendix 2: Conference Programme

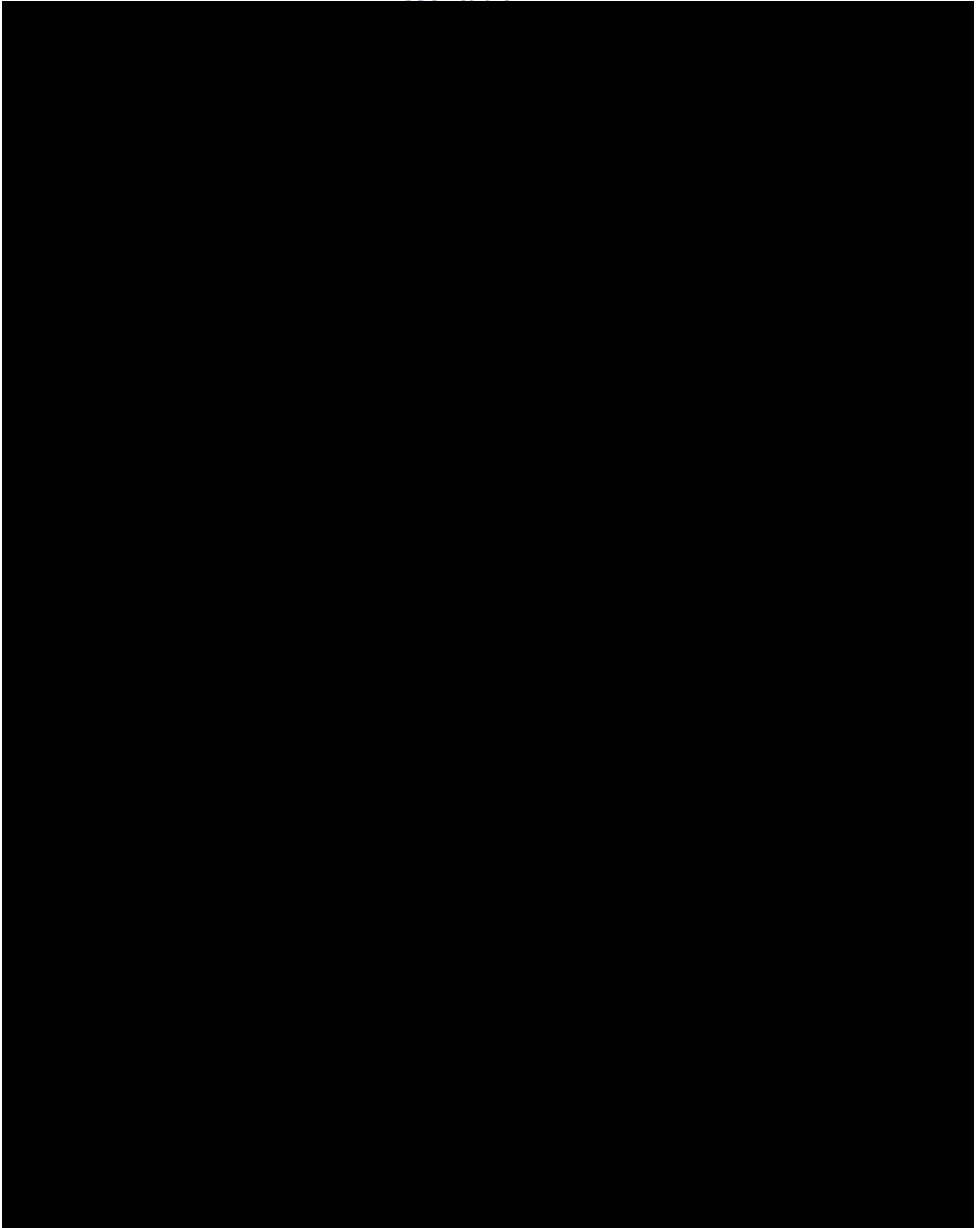
### 2011 Seminar programme

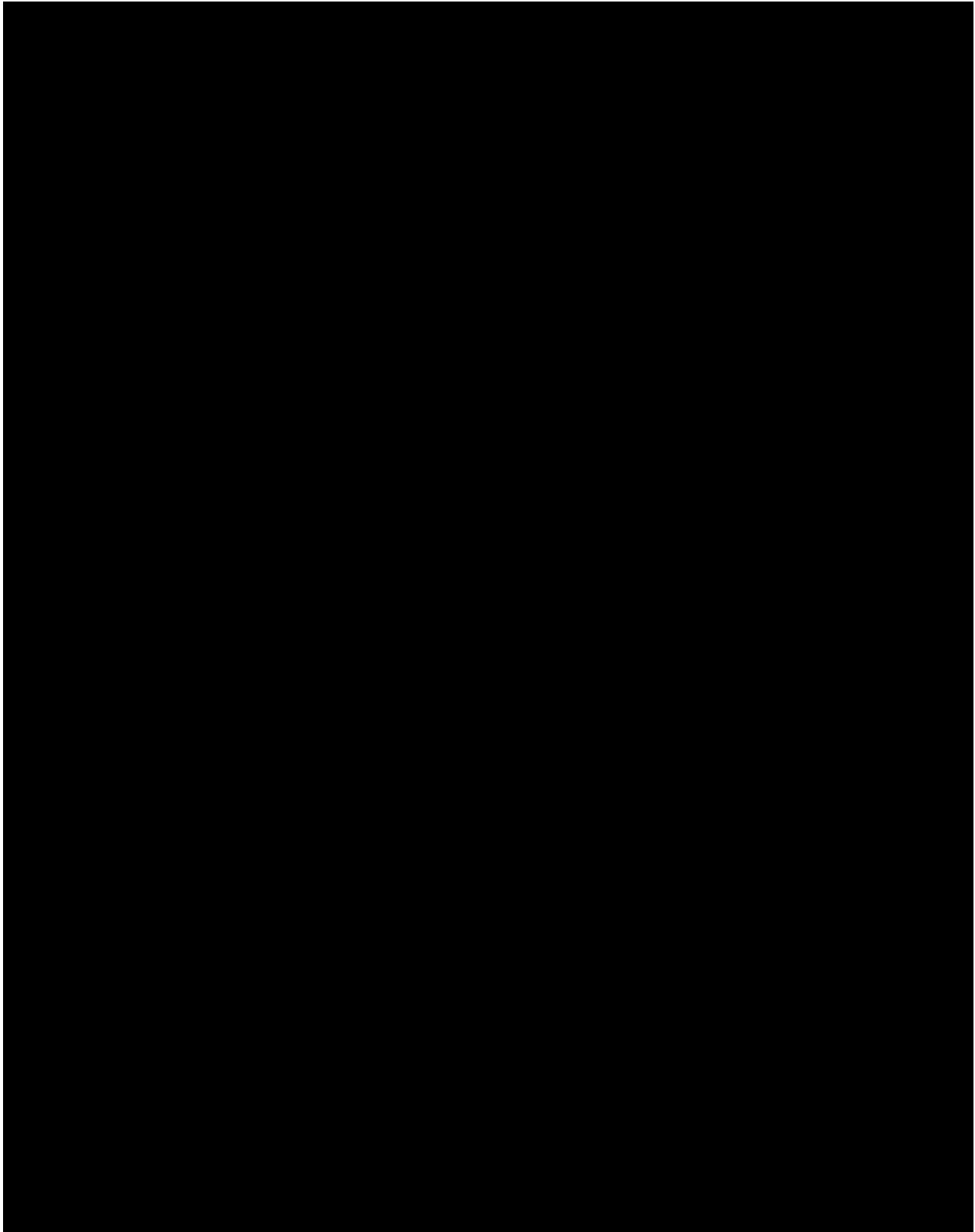
Sunday 6 <sup>th</sup> November			speaker
08.00 – 09.30		Registration	
09.30		Opening comments and housekeeping	Lyn Allen EDTNA/ERCA UK Key member
09.45- 10.15	Hospital based treatment	The development of the dialysis access nurse role in Leicester	Nick Brylka-Mee Dialysis Access Nurse Specialist Leicester Renal Unit
10.15.- 11.00		Immediate start PD	Gerry Endle Peritoneal dialysis sister Queen Alexandra Hospital, Portsmouth
11.00 – 11.30		Non-medical prescribing – a satellite experience!	Laura Stevens and Emma Burgin Loughborough Dialysis Unit
11.30 – 11.45	Coffee break		
11.45 – 12.15	Community based therapy	Home therapies	Richard Fluck President elect British Renal Society
12.15 – 12.45		Nocturnal dialysis	Suzanne Glover. Matron Harborough Lodge and Kettering dialysis units
12.45 – 13.15			
13.15 – 14.15			
14.15	Transplantation	<b>“Let’s try the scenic route without a sat nav!”</b>	Anne Theakstone Live Donor Coordinator Nottingham University Hospitals

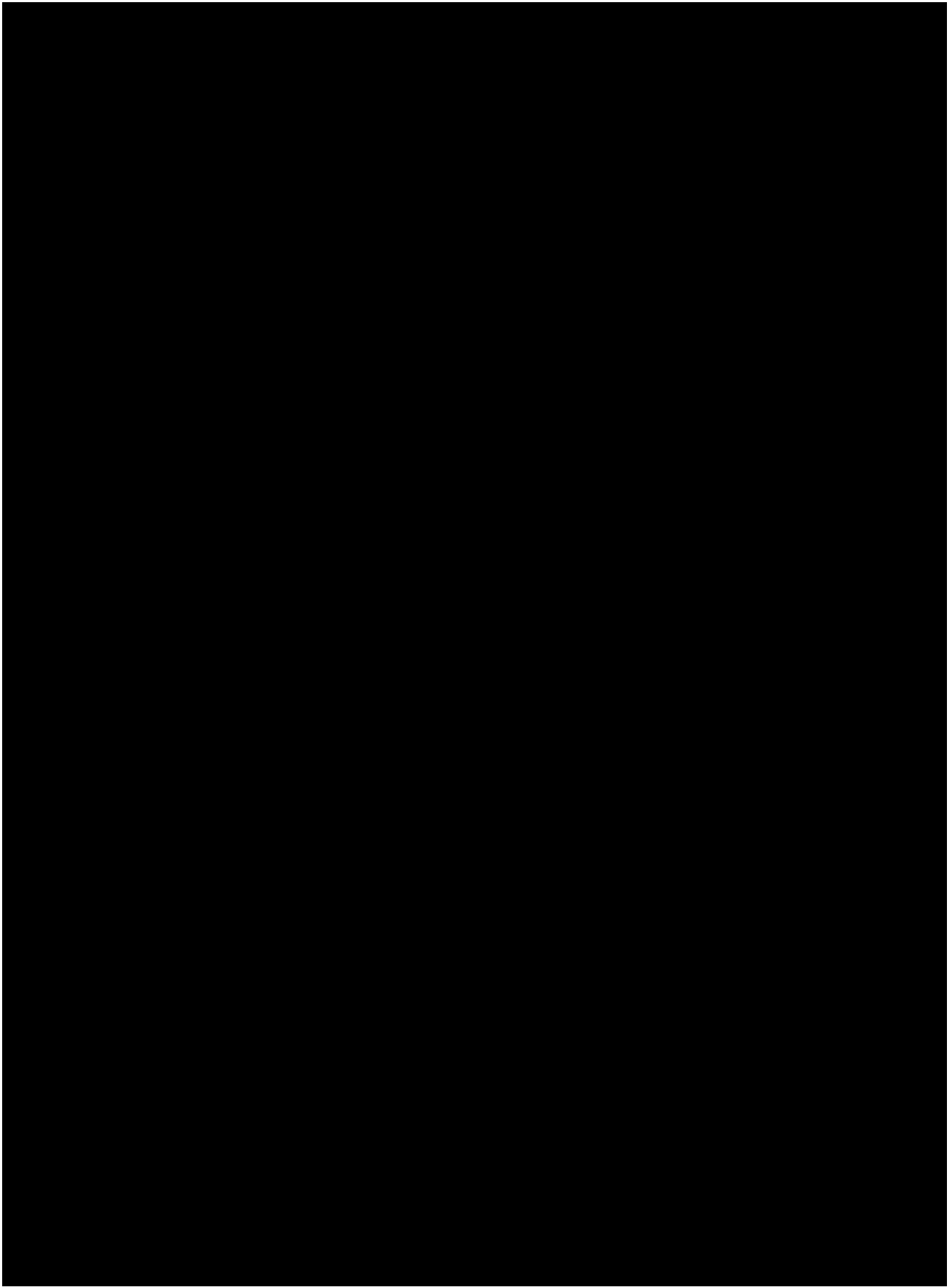
15.00		Non heart beating donation, where are we now	Richard Bowen Recipient Coordinator, Nottingham University Hospitals, and Liz Armstrong.
16.00 – 17.30	A developing ourselves Café		Diane Wilkinson Managing Director Aspiring to excellence.
19.30	Pre dinner drinks in conference foyer		
20.00	Evening meal and disco in conference room		
Monday 7 <sup>th</sup> November			
08.30 – 09.30		Registration	
09.30 – 09.40	Opening comments		Lyn Allen EDTNA/ERCA UK Key member
09.40 – 10.10		Patient Information	Andrew Mooney Consultant St James Hospital , Leeds
10.10 – 10.40		A patients perspective as an HD blogger	Trevor Dyer
10.40 – 11.00	Coffee break		
11.00 – 11.30	Impact of tariff and commissioning on the service	Regional commissioner perspective	Naseer Ahmed- Iqbal
11.30 – 12.00		Clinician perspective	Richard Fluck President Elect British Renal Society
12.00 – 12.30		Open panel for questions	
12.30 – 13.30	lunch		
13.30 – 14.00	Psychosocial care Psychosocial care	A survey of employment among dialysis patients in an East Midlands NHS Trust	Mary Quashie- Howard Leicester
14.00 – 14.15		Mind and Body Matters in Renal Care	Davina Wong Assistant Clinical psychologist Royal Free
14.15 –		Title to be confirmed	Fiona Willingham

14.30			Research fellow Derby
14.30 – 15.15		Depression and low mood in renal patients: recognising typical signs and symptoms'	Dr. Jenny Hainsworth Clinical Psychologist Chris Cutler Clinical Psychologist
15.15- 15.30		Tea break	
15.30 – 16.00		Chronic renal failure and depression: how to manage in everyday nursing practice'	Dr. Jenny Hainsworth Clinical Psychologist Chris Cutler Clinical Psychologist
16.00		Closing comments and evaluations	Lyn Allen

**Appendix 3: EDTNA/ERCA Mind and Body Matters in Renal Care  
Presentation**







# **SECTION D: SYSTEMATIC REVIEW**

# Quality of life after liver transplantation: An updated systematic review

## Introduction

Orthopic liver transplant is the treatment of choice for End Stage Liver Disease. With reports of 1 year survival rates of adults approximately 87%; 80.0% at 3 years and 75.1% at 5 years post-transplant (Cowling et al, 2004). The clinical outcomes continue to improve with fewer postoperative complications and more effective immunosuppression (Bravata et al, 1999). A key goal of liver transplantation is to allow patients to fully reintegrate into society as participating, active and productive members (Cowling et al, 2004). As survival rate following liver transplantation improves, focus on mortality and morbidity post-transplant can no longer be sufficient. Increased attention is required on quality of life post-transplant (Bownik et al, 2009).

### Quality of Life:

Quality of life factors are increasingly important targets of evaluation. Although there is considerable research on morbidity and mortality rates, less is known about the influence of the transplant procedure on health related quality of life of the recipient (Hicks, Larson and Ferrans, 1992). Bravata et al (1999) discussed the importance of a comprehensive measurement of post-transplant health related quality of life. From a recipient's perspective, many more patients are concerned about quality of life than longevity. Additionally many recipients may also have debilitating symptoms post-transplant including fatigue, bone pain, loss of self-esteem, depression and side effects from immunosuppressant medication, some of which do have adequate measures that can be used for evaluation of the symptom, however others that have no physical bodily manifestation are poorly measured by traditional outcome measures and conventional clinical testing (Younossi et al 1998). Bradley (2001) emphasises the importance of differentiating health status from quality of life. According to Singh and



Bradley (2006), the most essential feature of measuring quality of life is that it should capture the individual's subjective evaluation of their quality of life and not what others imagine it to be. Jay, Butt, Ladner, Skaro and Abecassis (2009) state that "The premise of organ transplantation in general and liver transplantation in particular is to return people to a state of health wherein they can return to a productive, fulfilling existence. This notion is at the heart of QOL measurement."

### **Generic vs Specific Quality of Life Measures:**

Quality of Life is a multi-dimensional concept (Taillefer, Dupuis, Roberge and Le May, 2003) with common measures tending to focus broadly on six domains including physical health, psychological health, social functioning, sexual functioning, ability to perform daily activities and general wellness (Younossi et al 1999). Bravata et al, (1999) completed a meta-analysis of health-related quality of life with findings suggesting that health-related quality of life was impaired pre-transplant but improved post-transplant. This study reported large gains in aspects of quality of life were most affected by physical health and smaller improvements in areas affected by psychological functioning.

Bravata et al's (1999) study included a wide range of HRQOL measures including four main generic scales which were combined by differences pre and post-transplant (Karnofsky Performance Status scale (KPS), Sickness Impact Profile (SIP), Nottingham Health Profile (NHP), and Medical Outcomes Survey Short Form 36 (SF-36). Other variations included one specific Liver transplant measure (NIDDK Liver Transplantation QOL survey) and other measures (Index of well-being, European Organisation for research and treatment of Cancer QOL questionnaire and Psychosocial Adjustment to Illness Scale-Self-Rate or self-developed questionnaires). The study provided valuable data outcomes concluding general improvements in patients' general health after transplantation, with further research required on why improvements in psychological health (including areas of social isolation and social functioning) were less consistent.

As shown in Bravata et al's (1999) study, various outcome measures have been used to indicate health related quality of life in liver patients. These tend to include generic instruments for use in patient who have chronic illnesses. The most commonly used is the SF36, with other measures such as the more recently developed SF-6D and the EQ-5D. However, one problem with measuring quality of life is that using a generic scale might not be appropriate for use with specific disease groups (Guyatt, Feeny, Patrick, 1993). Generic measures are necessary for comparing outcomes across different populations (e.g. those transplanted with the general population) and interventions (surgery vs medication); this might be particularly relevant for cost effectiveness. Jay et al (2009) reviewed 128 articles utilizing over 50 different QOL instruments. They found generic health status instruments most commonly used with the Medical Outcomes Study Short Form (SF-36) amongst them. The SF-36 was designed as a generic indicator of health status generally for population surveys and evaluative studies of health policy. Its advantage as a generic QOL measure is that it can be applied widely to a range of types and severities of conditions.

Disease-specific measures on the other hand, are specific to certain states, symptoms and concerns of the diagnostic group. Thus they may be more sensitive to detecting and quantifying small changes that are more important to the clinician or patient (Patrick & Deyo, 1989). Much fewer studies include targeted, disease-specific instruments. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Quality of Life questionnaire, the Liver Disease Quality of Life questionnaire, and the Chronic Liver disease questionnaire being the most frequently used targeted measures. However, these measures are specific to Liver disease rather than post-transplantation of the liver.

In a 2008 editorial of Liver Transplantation Dan and Younossi (2008) highlighted a study by Desai, Jamieson, Gimson, Watson, Gibbs, Bradley and Praseedom (2008) suggesting that the study was particularly strong due to its use of both generic and disease specific

measures. Through obtaining QOL data on both generic and disease specific levels researchers were able to gain a more rounded understanding of patient experiences.

### **Cross sectional vs Longitudinal Studies:**

Desai et al's (2008) study also stood out because it provided useful cross-sectional information on QOL of patients over 10 to 30 years following liver transplantation. This makes the study one of the first to provide quality of life data over a decade post organ transplant (Dan & Younossi, 2008), however, a record of pre-transplant QOL data is not taken with this study. Following this, a more recent systematic review by Tome, Wells, Said, Lucey (2008) identified 44 longitudinal studies using the SF-36. They concluded that there were significant post-transplant improvements in general QOL, social functioning, physical health and psychological health. Yet Tome et al's (2008) decision to use only the SF36 restricts its findings to general health status rather than specific to liver.

Bravata et al's (1999) study highlights the diversity of QOL instruments currently being used and Tome et al (2008) highlights the importance of longitudinal methods. Interestingly, many of these instruments are not designed to assess key symptoms and issues facing liver transplant recipients. There is a sense that with large numbers of QOL instruments there is a lack of knowledge around psychometric strengths and weaknesses that hinder the assessment of QOL findings for liver transplant in meaningful ways (Jay et al 2009). Additionally, focus on cross-sectional data, hampers any long-term and meaningful data through lack of longitudinal research design. With such advances in liver transplantation, the way forward with quality of life research in Liver Transplant is now to perfect study designs and measurements, utilizing the most appropriate tools to help with understanding individuals' recovery post-transplant, to enable patients return to a state of health that can be most productive and a fulfilling existence.

## **Objectives:**

This review intends firstly to assess the quality of life in adult liver transplant recipients following the evidence available since Tome et al's (2008) review. A second aim will be to focus on the quality of study designs, utilisation of longitudinal methods and disease specific measures.

## **Materials and Methods**

The current review intends to assess the quality of life in adult liver transplant recipients, paying particular attention to studies using the generic quality of life measure, SF36 and more specific measures for chronic liver disease. The review question was defined using PICOS by identifying the Patient Population/Problem, Intervention (treatment/test), Comparison (group or treatment), Outcome, and setting (see table 1).

Parameter	Inclusion Criteria	Exclusion Criteria
Patients	Adults over 18 years Patients eligible for liver transplant Liver transplant recipients	Patients under 18 years of age
Intervention	Liver Transplant	
Comparator	Pre liver transplant and Post liver transplant comparisons (may be separate cohorts but still comparable) Longitudinal study of the same individual before and after liver transplantation	
Outcomes	Generic measures of quality of life - SF36 - Specific liver related measures of quality of life e.g. the Chronic Liver Disease Questionnaire	
Study Design	Case controlled studies Longitudinal studies Before and after studies Interrupted time series studies	Editorials and opinion pieces Conference abstracts that have not been published as journal articles

***Table 1: Inclusion and Exclusion criteria using PICOs***

### **Ethical and Other Restrictions:**

Randomised controlled trials are traditionally seen to be the ‘Gold Standard’ in systematic reviews. However it is important to note that in investigating health interventions such as transplantation, an ethical dilemma is raised. Surgical operations such as transplantation cannot be allocated in a ‘randomised’ fashion. In the case of most countries, individuals are assessed for transplant with the intention to be placed on a waiting list until a suitable donor organ is made available. Exceptions are made in the case of potential live donation where the surgery has more potential to be planned. However, in the case of liver transplant, live donation is not as readily available as other types of donation such as kidney transplant due to the increased risk to the donor. Therefore randomised controlled trials are

unlikely for this research question and if a study were to be found which uses randomisation it would require further ethical scrutiny.

Only English written articles will be included for the purpose of this review. Due to the limitations of the researcher's translation capabilities, it is not possible to include articles that are written in any other language unless they have been translated to English.

### **Search Strategy:**

Study identification will include both manual and electronic searching strategies. Electronic searches will involve the electronic databases and search terms listed below. The initial selection criteria will be broad to ensure that as many studies as possible are assessed as relevant for the review. Any articles that are clearly unsuitable (i.e. articles presenting papers not relating to liver transplant or not meeting the criteria stated above) will be excluded at an early stage using abstracts and titles presented in electronic catalogues. Other articles will be excluded after they have been read and reviewed using a 'Study Eligibility Form' (see Appendix 1: Study Eligibility Form) with a more thorough review of the methodology. At the review stage, two reviewers will separately use the 'Study Eligibility Form' to assess inclusion. The second reviewer (HI) was not as familiar with liver transplant procedures and thus decisions for inclusion were discussed but primarily made by the first reviewer (DW).

### **Electronic Search Strategy:**

Similar to Tome et al (2008) the literature search focused on three medical databases including Embase, Cochrane and Pub Med for a first phase search strategy. A second phase of electronic databases search included PsychInfo, Medline and CINAHL however no new relevant articles arose from Medline and CINAHL. A further 'hand-search' of reference lists of included articles. The contents list of 'Liver Transplantation' between January 2007 to September 2015 was also searched for relevant articles. Any conference abstracts identified were followed up with internet searches of publications potentially resulting from the abstracts.

### **Search Terms:**

Tome et al's (2008) paper used coordinated search terms were used including "liver transplantation"; "quality of life"; "employment"; "sexuality"; "gender"; and "health status". Using that as guidance, this review started with (*Liver transplant\**) AND (*quality of life*) as initial search terms, building on the search strategy to include: AND (*SF36 OR Short Form 36*) OR (*Chronic Liver Disease Questionnaire*) with the included time frame. Searches were carried out without language restrictions however non-English written articles were excluded at reviewer stage.

### **Assessing Risk of Bias:**

The authors carried out a pilot on a couple of studies that were considered eligible using the "Cochrane Risk of Bias Assessment Tool: for Non-Randomised Studies of Interventions" (ACROBAT-NRSI) and the Quality Assessment Checklist taken from the 'National Institute for Health' (NIH). As discussed previously, it was unlikely for a review question focusing on liver transplant to include randomized controlled trials. Following initial study eligibility screening, 'before and after' and 'case-control' studies were the predominant study designs included thus the ACROBAT-NRSI and the NIH Quality Assessment Checklists for 'Before and After Studies' and 'case control studies' appeared the most appropriate tools for assessing bias for both types of study design, the pilot provided the authors the opportunity to test which assessment tool could be used most appropriately and with ease. Following the pilot, the NIH Quality Assessment Checklist was used and adapted using a few questions from the AROBAT-NRSI and additional signalling questions reviewing 'Bias in measurement of outcomes' (see Appendix 2: Assessment of Bias tool). All included articles were then assessed by two reviewers independently. Discrepancies were discussed between the two reviewers until a consensus was reached.

### **Seven areas were assessed for risk of bias including:**

Assessment of specification of study goals and objectives; bias of selection of participants into the study; bias in limited sample size; bias in measurement of interventions; bias in measurement of outcomes; bias due to missing data; bias in selection of the reported results. Signalling questions were asked for each area of potential bias and rated as 'yes'; 'no'; 'cannot determine'; 'Not Applicable' or 'Not Reported'. As far as possible, 'yes' or 'no' answers were used for definitive answers. A higher number of 'yes' responses indicated a better quality study, unless the reviewer stated otherwise. Each study was reviewed as unique in its own right for fairness in review of the design, methodology and reporting. Studies by Jüni, Witschi, Bloch, & Egger, (1999) and Colle, Rannou, Revel, Fermanian, & Poiraudau, (2002) suggest that the use of scales with summary scores to distinguish high and low quality studies is questionable and not recommended because the weighting assigned to each methodological item can vary considerably between the scales and often does not take into account the direction of bias. Therefore bias ratings were limited to 'yes' or 'no' answers primarily, although this review did not presume any direction the bias.

## Results

### Study selection:

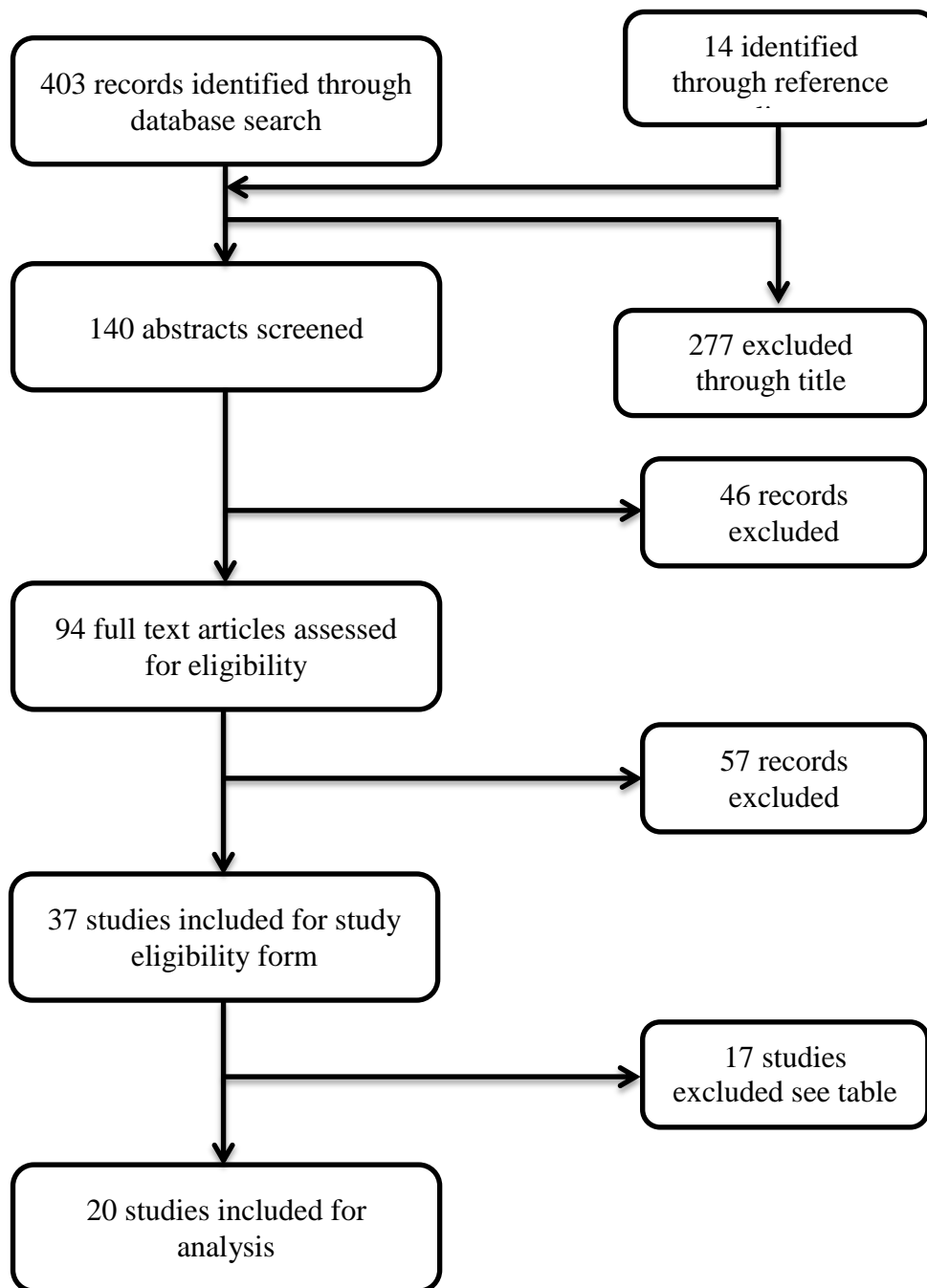
Database screening process highlighted 403 abstract titles that were reviewed as potentially eligible, with 140 abstracts which were then screened (126 through database screening and 14 abstracts through references). Abstract review excluded 46 articles leaving 94 full text articles which were assessed. Of the 94 full text articles assessed, 57 studies were excluded due to participants being donors, not transplant recipients or not liver transplant (other forms of organ transplant or medication management), outcome measures not measuring QOL and some duplicates spotted and one conference abstract only. There were 37 studies whose methodology was more closely reviewed using a Study Eligibility Form, 17 excluded following review from 2 assessors (DW and HI) (see table 2 for Reasons for



Exclusion); 20 articles were finally selected for assessing risk of bias. Results of the search are summarized in Figure 1.

<b>Exclusion Reason</b>	
1	Pre-measures were taken for MELD scores and CPT scores but not SF36 and therefore post-measures for SF36 had no pre-comparison
2	The comparison group was Decompensated Cirrhosis patients vs post-transplanted patients. Paper excluded based on Decompensated cirrhosis patients not all eligible for transplantation, thus unfair comparison.
3	No pre-transplant measure taken before transplantation. The first measure is 6 months post-transplant
4	The comparison group was Cirrhosis patients vs post-transplanted patients. Paper excluded based on cirrhosis patients not all eligible for transplantation, thus unfair comparison.
5	Age range is 15-70. SR includes only 18+ participants
6	No pre and post-transplant group. Baseline is up to 15 years post-transplant (from a previous study)
7	Duplicate results
8	There is no comparison group only post-transplant measured
9	There is no post-transplant comparison group as patients were on the waiting list but not transplanted
10	This is a study protocol which has not yet been completed and results have not yet been published
11	The WHOQOL was employed, not the SF36
12	The comparison group was Cirrhosis patients vs post-transplanted patients. Paper excluded based on cirrhosis patients not all eligible for transplantation, thus unfair comparison.
13	Duplicate results
14	Although pre-transplant measures were taken, no SF36 was included in pre-transplant measures only post-transplant
15	Although pre-transplant measures were taken, there was no pre-transplant quality of life score
16	There is no post-transplant comparison group
17	Duplicate results #14 used in table 3 used because results were reported more clearly

***Table 2: Reasons for Exclusion***



*Figure 1: Flow chart summary of database search*

### **Study characteristics:**

Characteristics of the 21 studies reviewed are presented in table 3. USA provided the largest number of studies (7) with Spain and Japan carrying out 4 and 3 respectively. Two studies from Spain carried out by Ortega et al (2009a and 2009b) used a sample from the same clinical trial comparing QOL in different types of organ transplantation. Both studies were included because one, #9 focused on the SF36, due to its comparisons across different organ transplants and #10 included the LDQOL measure.

Several authors targeted specific liver disease groups e.g. Study #5, on level of steroid prescribed post-transplant and its impact on QOL; #6 and #7 targeted quality of life in alcoholic liver disease specifically; #8 targeted hereditary hemorrhagic telangiectasia and severe hepatic involvement; #14 targeted uncertainty, women and Primary Biliary Cirrhosis. All studies from Japan (#3, #15, and #16) targeted living donor transplants only.

### **Domain findings:**

Table 4 indicates SF36 domain findings. All but one study showed improvement in QOL. Use of LDQOL and CLDQ was reported in a variety of ways and with different labels for each domain, therefore it was difficult to collate results in a cohesive table. However all studies using specific measures indicated improvements post-transplant.

First author	Year	Country of origin	Study Design	Population	No participants	QOL Outcome measures	Duration of participation	Findings
1. Tryc et al	2014	Germany	Before and after study	Eligible transplant candidates tested before and after	50 patients altogether measured pre and post-transplant	SF36	At least 12 months post-transplant	Health related quality of life improved overall after Orthotopic Liver transplant Significant changes in General Health (GH) ( $p = 0.01$ ), Vitality (V) ( $p = 0.02$ ), mental health (MH) ( $p = 0.04$ )
2. Mabrouk et al	2012	Egypt	Case controlled study	Transplant candidates vs Transplant Recipients	153 – 103 post-transplant, 50 pre-transplant	SF36 LDQOL	Cross sectional study using one time point, 4-5 months post-transplant	HRQOL scores of both generic; SF36 and 1/12 (96%) of the disease-specific domains were significantly higher in Liver Transplant cohort compared to controls ( $p < 0.01$ )
3. Yamanouchi et al	2012	Japan	Before and after study	Eligible transplant candidates tested before and after	20 – 13 hepatectomy, 7 living donor transplant	SF36	At least 12 months post-transplant	Before the operation the scores of all QOL subscales except PF were significantly lower in the live donor liver transplant group vs hepatectomy group. 12 months post-surgery there were no sig differences. Both types of transplantation showed sig better QOL ( $p < 0.05$ for both types)
4. Sirivatanauksorn et al	2012	Thailand	Case controlled study	Transplant candidates vs Transplant recipients	116 – 59 post-transplant, 57 pre-transplant	SF36 CLDQ	Cross-sectional study using one time point, 3 months	Post-transplant patients, spouses and caregivers showed significantly better generic QOL and CLDQ scores in all domains
5. Zaydfudim et al	2012	USA	Before and after study	Eligible transplant candidates tested before and after	794 – 608 transplanted 186 awaiting transplant	SF36	Maximum 74 months	After controlling for pre-transplant HRQOL, time post-transplant, pre-transplant diagnosis group and temporally associated episodes of rejection, post-transplant high-dose steroid use was associated with lower PF ( $p < 0.001$ ) and MH ( $p = 0.049$ )
6. Telles-	2011	Portugal	Before and	Eligible	45 - 28	SF36	At least 12	Significant improvement in all mental health and

	Correia et al		after study	transplant candidates tested before and after	transplanted 17 awaiting transplant		months post-transplant	quality of life dimensions among alcoholic liver disease group
7.	Eshelman et al 2010	USA	Before and after study	Eligible transplant candidates pre tested before and after	65 patients altogether measured pre and post-transplant	SF36	6 months post-transplant	Significant improvement between 1 and 6 month post-transplant follow up ( $p<.001$ ) but not between month 0 and 1 and 0 and 6. MH improved significantly between 0 and 1 month follow up ( $p<.001$ ) but not between 0 and 6
8.	Dupuis-Girod et al 2010	France	Before and after study	Same participants, pre-transplant date taken in retrospect	13 patients altogether measured pre and post-transplant	SF36	109 months	All patients reported an improvement in the QOL after OLT.
9.	Ortega et al 2009a	Spain	Before and after study	Eligible transplant candidates tested before and after	159 pre-transplant 108 post-transplant	SF36	At least 12 months post-transplant	Significant improvements in QOL post-transplant in almost all dimensions of SF36
10.	Ortega et al 2009b	Spain	Before and after study	Eligible transplant candidates tested before and after	159 pre-transplant 108 post-transplant	SF36 LDQOL	At least 12 months post-transplant	All domains showed significant improvements in SF36 at 3 months after transplantation with only slight improvements at 12 months. For LDQOL the dimensions with sig differences were effects of Liver disease on activities on daily living; concentration; health distress; sleep problems; stigma of liver disease and sexual function
11.	Russell et al 2008	USA	Before and after study	Eligible transplant candidates pre tested before and after	104 patients altogether measured pre and post-transplant	SF36	4 years	Scores on all SF36 measures improved from pre to post-transplant

12.	Gotardo et al	2008	Brazil	Case controlled study	Transplant candidates vs Transplant recipients	65 pre-transplant, 61 post-transplant	SF36 LDQOL	Cross sectional one time point only between 6 months to 5 years post-transplant	SF36 and LDQOL both showed significantly worse scores for patients awaiting transplant than post-transplant
13.	Rodrigue et al	2010	USA	Case controlled study	Transplant candidates vs Transplant recipients	205 – 110 pre-transplant, 95 post-transplant	SF36v2	Cross sectional one time point only over 3 months post-transplant	Hi fatigue severity was associated with significantly compromised scores on most SF36 domains
14.	Lasker et al	2011	USA and online	Case controlled study	Transplant candidates vs Transplant recipients	100 – 25 waiting list, 75, post-transplant	SF36	Cross sectional one time point only	Results confirmed substantial improvements with transplant, as expected but showed continued deficits to national norms
15.	Togashi et al	2013	Japan	Before and after study	Eligible transplant candidates pre tested before and after	51 patients altogether measured pre and post-transplant	SF36v2	18 months	Among patients with severe liver disease requiring live donor LT, HRQOL significantly improves after transplantation to levels comparable to those of health controls in some dimensions
16.	Urano et al	2013	Japan	Before and after study	Eligible transplant candidates pre tested before and after	10 patients altogether measured pre and post-transplant	SF36	24 months	This study demonstrated differences in the recovery time of nutritional metabolism function, serum biochemical data and HRQOL in Live donor LT patients. Hepatic protein synthesis capacity and the physical score in HRQOL were shown to require long recovery
17.	Martin-Rodriguez et al	2014	Spain	Case controlled study	Transplant candidates vs Transplant recipients	153 – 51 pre-transplant, 51 post-transplant, 51 pre-waiting list	SF36	Cross sectional one time point only	Both pre-waiting list and post-transplant scores were better on all dimensions than pre-waiting list candidates. Psychological treatments are also necessary during the entire medical transplant protocol to achieve better biopsychosocial

							adjustment.		
18.	Perez San Gregorio et al	2010	Spain	Before and after study	Eligible transplant candidates tested before and after	27 patients altogether measured pre and post-transplant	SF36 EUROQOL	12 months post-transplant	Liver transplant significantly improves quality of life of patients with end stage liver disease
19.	Russell et al	2008	USA	Before and after study	Eligible transplant candidates tested before and after	104 patients altogether measured pre and post-transplant	SF36	Between 1 month to 4 years	Overall improvement in mental and physical HRQOL after liver transplantation
20.	Telles-Correia et al	2009	Portugal	Before and after study	Eligible transplant candidates tested before and after	60 patients altogether measured pre and post-transplant	SF36	6 months post-transplant	Findings suggest that mental and physical components of quality of life improved early after liver transplantation (month 1). At 6 months only the physical component of QOL showed further improvement

*Table 3: Characteristics of included studies*

First author	Year	Study Design	Final SF36 findings on each domain*									PC and summary	MC
			PF	RP	BP	GH	V	SF	RE	MH			
1. Tryc et al	2014	Before and after study	+	+	+	+	+	+	+	+	+	NR	
2. Mabrouk et al	2012	Case controlled study	+	+	+	+	+	+	+	+	+	NR	
3. Yamanouchi et al	2012	Before and after study	+	+	+	+	+	+	+	+	+	NR	
4. Sirivatanauksorn et al	2012	Case controlled study	+	+	+	+	+	+	+	+	+	NR	
5. Zaydfudim et al	2012	Before and after study	NR	NR	NR	NR	NR	NR	NR	NR	NR	PC + MC +	



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6.	Telles-Correia et al	2011	Before and after study	NR	NR	NR	NR	NR	NR	NR	NR	PC + MC +
7.	Eshelman et al	2010	Before and after study	NR	NR	NR	NR	NR	NR	NR	NR	PC + MC +
8.	Dupuis-Girod et al	2010	Before and after study	+	+	0	+	+	+	+	+	NR
9.	Ortega et al	2009a	Before and after study	+	+	+	+	+	+	+	+	Close to General population
10.	Ortega et al	2009b	Before and after study	+	+	+	+	+	+	+	+	Reported from #9
11.	Russell et al	2008	Before and after study	+	+	+	+	+	+	+	+	PC + MC + Close to General population

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12.	Gotardo et al	2008	Case controlled study	+	+	+	+	+	+	+	+	NR
13.	Rodrigue et al	2010	Case controlled study	NR	NR	NR	NR	NR	NR	NR	NR	NR
14.	Lasker et al	2011	Case controlled study	+	+	+	+	+	+	+	+	NR Remained lower than general population
15.	Togashi et al	2013	Before and after study	+	+	+	+	+	+	+	+	NR Remained lower than general population
16.	Urano et al	2013	Before and after study	+	+	+	+	+	+	+	+	NR Remained lower than general population
17.	Martin-Rodriguez et al	2014	Case controlled study	+	+	+	+	+	+	+	+	NR
18.	Perez San Gregorio et al	2010	Before and after study	+	+	+	+	+	+	+	+	NR

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19.	Russell et al	2008	Before and after study	+	+	+	+	+	+	+	+	Remained lower than general population
20.	Telles-Correia et al	2009	Before and after study	NR	NR	NR	NR	NR	NR	NR	NR	PC + MC +

*Table 4: SF36 domain findings*

### **Assessing risk of bias:**

All studies used a version of the SF36, 2 studies used the SF36 v 2 and several used versions translated to the language of the study origin. Only 4 studies used a specific measure alongside the SF36. A majority of 14 studies were ‘before and after’ study design and longitudinal in method i.e. gathering data from the same studies repeatedly. Due to the clinical nature of liver transplant, no studies discussed issues of statistical power and sample sizes appeared to be on the smaller end of the scale. Results of the assessment of bias are shown in table 5 and 6. One study with longitudinal study design received a quality rating of ‘Good’ due the methodology and use of specific quality of life measure. Three cross-sectional studies used specific measures (1 used chronic liver disease questionnaire – CLDQ; 2 used Liver disease quality of life – LDQOL).

First Author	Year	Specificati on of study goals and objectives	Bias in selection of participants into the study	Bias in limited sample size	Bias in measurement of interventions	Bias in measurement of outcomes	Bias due to missing data	Bias in selection of the reported results	Quality rating (Good, Fair or Poor)	Comments
1. Tryc et al	2014	Good	Good	Fair	Good	Fair	Fair	Good	Fair	A few aspects are not reported regarding statistical power and patients who were lost to follow up/died/required re-transplantation were reported but data not accounted for. Only generic measure of QOL is used. As this is main purpose of review, it is taken strongly into account.
3. Yamouchi et al	2012	Good	Poor	Fair	Good	Fair	Not-reported	Fair	Poor	A lot of key information was not reported, which made it more difficult to assess the quality of this paper.
5. Zaydfudim et al	2012	Good	Good	Good	Good	Fair	Fair	Good	Fair	Generally good, marked down for not using specific measure and not reporting on power. Method tried to accommodate for missing data but this could be made explicit in results and managing missing data. No statistical adaptation for missing data
6. Telles-Correia et al	2011	Good	Good	Fair	Good	Fair	Not-reported	Good	Fair	Some information is not reported and there is a lack of specific measure. Study design is good.
7. Eshalman et al	2010	Good	Good	Fair	Good	Fair	Fair	Good	Poor	Over 20% missing data reported but not accounted for in statistics. Study was a component of a larger trial, not specifically looking at QOL thus design was not specific for purpose. Lack of use of specific LT measure.
8.	2010	Good	Good	Poor	Good	Fair	Not-reported	Fair	Poor	Study is limited by a small sample

Dupuis-Girod et al											size and lacks reporting of missing data or explanation of small sample size (out of 753 patients only 13 transplanted and included. Bias from retrospective reporting of QOL measure
9. Ortega et al	2009	Good	Not-reported	Good	Good	Fair	Not-reported	Good	Poor	Poor transparency in study, inability to replicate, does not report methodology or statistical analyses used, missing data or population used	
10. Ortega et al	2009	Good	Good	Good	Good	Good	Not-reported	Good	Good	This is a more detailed version of #10, lacks reporting of missing data however, better transparency and use of specific QOL measure.	
11. Russell et al	2008	Good	Good	Good	Good	Fair	Not-reported	Good	Fair	No specific measure of QOL, no reported missing data – it looks like only data from completed scores taken.	
15. Togashi et al	2013	Good	Good	Fair	Good	Fair	Fair	Fair	Fair	Missing data reported but over 20% of missing data and appears only completed data has been used for analysis	
16. Urano et al	2013	Good	Poor	Poor	Not-reported	Fair	Not-reported	Fair	Poor	This study has a limited and very specific sample size, receiving different medical interventions. Also lacks in methodology, missing data and specific measure.	
18. Perez San Gregorio et al	2010	Good	Good	Poor	Good	Fair	Not-reported	Good	Fair	Some information is not reported and there is a lack of specific measure. Small sample.	
19. Russel et al	2008	Good	Good	Fair	Good	Fair	Not-reported	Good	Fair	Some information is not reported and there is a lack of specific measure. Small sample.	

20. Telles- Correia et al	2009	Good	Poor	Fair	Fair	Fair	Not-reported	Fair	Poor	Poorly written and explained, lacks information and detail, lacks reporting missing data and no specific QOL
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*Table 5: Assessment of Bias – Before and After studies*

First Author	Year	Specific ation of study goals and objectives	Bias in selection of participants into the study	Bias in limited sample size	Bias in measurement of interventions	Bias in measurement of outcomes	Bias due to missing data	Bias in selection of the reported results	Quality rating (Good, Fair or Poor)	Comments
2. Mabrouk et al	2012	Good	Fair	Fair	Good	Fair	Not-reported	Good	Fair	Poor reporting and clarity, statistical power and missing data not reported. However study includes both generic and non-specific QOL measures. The comparison group is small in comparison to post-LT (50 vs 103).
4. Sirivatanauksorn et al	2012	Good	Poor	Poor	Good	Good	Not-reported	Poor	Poor	Although good in some areas, methodology is poorly described, not replicable because of lack of transparency in reporting. Combines patients and spouses/caregivers in sample size but reports only patients. Good use of specific measure.
12. Gotardo et al	2008	Good	Good	Fair	Good	Good	Not-reported	Good	Fair	Statistical power and missing data not reported. Better description of sample required. Good use of specific QOL measure. Would have met better quality rating if longitudinal and before and

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										after study.	
13.	Rodrigue et al	2010	Good	Good	Good	Good	Fair	Not-reported	Poor	Poor	Some information is not reported and there is a lack of specific measure. Small sample. Does not report QOL outcome in results sleep quality.
14.	Lasker et al	2011	Good	Good	Fair	Good	Fair	Good	Good	Fair	Study reports missing values and makes appropriate statistical adaptations. Would have been better with a specific measure
17.	Martin-Rodriguez et al	2014	Good	Fair	Fair	Good	Fair	Not-reported	Good	Fair	Good matching of gender and age and random sampling used but sample size is male heavy and no specific measure used.

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**Table 6: Assessment of Bias – Cross sectional studies**



## Discussion

There are many studies measuring the QOL following liver transplant. Indeed Bravata et al (1999) and Tome et al (2008) have demonstrated prior to this review an array of studies previously carried out. However, as transplantation advances and more studies begin to focus on the patients experience following transplant, study designs need to incorporate the patients' true perspective whilst utilising the most effective measurement tools. Tome et al (2008) highlighted several biases in their review. For example many studies exclude the very ill and QOL measures are sometimes taken too soon after transplant. This was similar within this review. Majority of studies did not report missing data and when data not used was reported it was often because patients had died or had been lost to follow up, possibly also indicating the exclusion of patients who are too unwell. Tome et al (2008) also highlighted that the range of QOL measurements and multiple study designs was a significant drawback. This study focused on the design and measurement tool flaws indicated by Tome et al's study and assessment of bias focused on these areas to indicate studies of stronger quality and where weaknesses still lie in current QOL studies.

Twenty studies were found examining the quality of life following Liver transplant, highlighting the overall effectiveness of liver transplantation. The main results of the review indicated that all but one study (#3) showed improvements in quality of life measures when using the SF36 generic measure of QOL. Only 4 out of 20 studies used a specific measure for liver, however only 3 studies used a specific measure (CLDQ and LDQOL). Specific measures also indicated improved quality of life following transplant. Overall study designs have increased in the number of before and after, longitudinal type studies; this review found 14 out of 20 studies utilising same participants, measured before and after transplant.

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# **SECTION D: APPENDICES**



# **APPENDICES: SYSTEMATIC REVIEW**

## Appendix 1: Study Eligibility Form

### STUDY ELIGIBILITY FORM

**Review title**

**Quality of Life in Liver Transplant Recipients: an updated systematic review**

<b>Study title:</b>		
<b>Study ID number:</b>	<b>First Author:</b>	<b>Year published</b>
<b>Notes:</b>		

<b>General Information</b>
<b>Date form completed:</b>
<b>Initials of person extracting data:</b>
<b>Reference citation (<i>Medline</i>):</b>
<b>Full reference and contact details:</b>
<b>Publication type (<i>full report, abstract</i>):</b>
<b>Notes:</b>

Factors	Assessment	Comments
<b>1. Type of Study</b>		
<p>Is the study any of the following? Please tick:</p> <input type="checkbox"/> RCT <input type="checkbox"/> Quasi-experimental (inc non-randomised controlled studies, before and after study, Interrupted time series) <input type="checkbox"/> Case control studies <input type="checkbox"/> Case series studies	<p>Yes      Unclear      No</p> <p>↓           ↓           ↓</p> <p><b>Exclude</b></p>	
<b>2. Participants</b>		
<p>Do patients have a diagnosis of chronic liver disease requiring transplantation?</p>	<p>Yes      Unclear      No</p> <p>↓           ↓           ↓</p> <p><b>Exclude</b></p>	
<p>Are the participants adults aged 18+?</p>	<p>Yes      Unclear      No</p> <p>↓           ↓           ↓</p> <p><b>Exclude</b></p>	
<b>3. Interventions</b>		
<p>Did participants receive any of the following types of liver transplant?:</p> <input type="checkbox"/> Liver transplant from deceased donor <input type="checkbox"/> Living donor liver transplant <input type="checkbox"/> Split donation transplant	<p>Yes      Unclear      No</p> <p>↓           ↓           ↓</p> <p><b>Exclude</b></p>	
<b>4. Types of comparison</b>		
<p>Who is the comparison group?</p> <input type="checkbox"/> Same participants, pre and post transplantation <input type="checkbox"/> <i>transplant candidates vs transplant recipients?</i>	<p>Yes      Unclear      No</p> <p>↓           ↓           ↓</p> <p><b>Exclude</b></p>	

<b>5. Outcomes</b>		
Did study report any of the following outcomes? Please tick: <input type="checkbox"/> SF36 <input type="checkbox"/> SF36 v 2 <input type="checkbox"/> CLDQ <input type="checkbox"/> other specific measure for quality of life in chronic liver disease/liver transplant	<p>Yes      Unclear      No</p> <p>↓           ↓           ↓</p> <p><b>Exclude</b></p>	
<b>FINAL DECISION</b>	<b>INCLUDE EXCLUDE</b>	<b>UNCLEAR</b>

**DO NOT PROCEED IF STUDY EXCLUDED FROM REVIEW**

**Characteristics of Included Studies**

**Methods**

	<b>Descriptions as stated in report/paper</b>	<b>Notes/Location in text</b>
<b>Aim of study</b>		
<b>Study design</b>		
<b>Outcome measures</b>		
<b>Start date</b>		
<b>End date</b>		
<b>Duration of participation</b> (from recruitment to last follow up)		
<b>Ethical approval needed/obtained for study</b>		

	<b>Description</b>	<b>Location in text</b>
<b>Population description</b> (from which study participants are drawn)		
<b>Setting and context</b> (including but not limited to healthcare system characteristics and health financing – e.g. user fees or financial coverage of services – as well as social context)		
<b>Inclusion criteria</b>		
<b>Exclusion criteria</b>		

<b>Methods of recruitment (e.g. phone, mail, clinic, patients)</b>		
<b>Informed consent obtained</b>		
<b>Total no. Subjects</b>		
<b>Withdrawals and exclusions</b>		
<b>Missing data</b>		
<b>Outcome(s) Primary and Secondary</b>		
<b>Cofounding factors/effect modifiers accounted for</b>		
<b>Authors' reported limitations of study's methods/results</b>		
<b>Notes:</b>		

Other information

<b>Study funding sources (including role of funders)</b>		
<b>Possible conflict of interest</b>		
	<b>Description as stated in report/paper</b>	<b>Location in text or source</b>
<b>Key conclusions of study authors</b>		
<b>References of other relevant studies</b>		
<b>Correspondence required for further study information</b> (from whom, what and when)		
<b>Notes</b>		

## Appendix 2: Assessment of Bias Tool

**Quality Assessment Checklist. Adapted from National Institutes for Health (National Heart, Lung, and Blood Institute) website for *Before and After Studies***

**Controlled before-and-after study Definition (from <http://childhoodcancer.cochrane.org/non-randomised-controlled-study-nrs-designs>)**

A study in which observations are made before and after the implementation of an intervention, both in a group that receives the intervention and in a control group that does not.

Criteria	Yes	No	Other (CD,NR, NA)*
<p><b><u>Specifications of study Goals and Objectives</u></b>  <b><i>Was the study question or objective clearly and appropriately stated?</i></b>            Did the authors describe their goal in conducting this research? Is it easy to understand what they were looking to find?  <i>This issue is important for any scientific paper of any type. Higher quality research explicitly defines a research question. A 'yes' would indicate this study has met this criteria.</i></p>			
<p><b><u>Bias in selection of participants into the study</u></b>  <b><i>Were eligibility/selection criteria for the study population pre-specified and clearly described?</i></b>            Did the authors describe the eligibility criteria applied to the individuals from whom the study participants were selected or recruited? In other words, if the investigators were to conduct this study again, would they know whom to recruit, from where, and from what time period? A 'yes' would indicate this study has met this criteria  <b><i>Were the participants in the study representative of those who would be eligible for the test/service/intervention in the general or clinical population of interest?</i></b>            The participants in the study should be generally representative of the population in which the intervention will be broadly applied. Studies on small demographic subgroups may raise concerns about how the intervention will affect broader populations of interest. For example, interventions that focus on very young or very old individuals may affect middle-aged adults differently. Similarly, researchers may not be able to extrapolate study results from patients with severe chronic diseases to healthy populations. A 'yes' would indicate 'good' quality.  <b><i>Were all eligible participants that met the pre-specified entry criteria enrolled</i></b>            To further explore this question, reviewers may need to ask: Did the investigators develop the inclusion/exclusion criteria prior to recruiting or selecting study participants? Were the same underlying I/E criteria used for all research participants? Were all subjects who met the I/E criteria enrolled in the study? Look out for cases of exclusion and why they were excluded. A 'yes' to all the above questions would indicate 'good' quality unless good reason for exclusions applied. Would exclusions have influenced results? Selection bias can occur when selection of patients is related to intervention and outcome.</p>			

<p><b><u>Bias in limited sample size</u></b>  <b><i>Was the sample size sufficiently large to provide confidence in the findings?</i></b></p> <p>Did the authors present their reasons for selecting or recruiting the number of individuals included or analysed? Did they note or discuss the statistical power of the study?</p> <p><i>This question addresses whether there was a sufficient sample size to detect an association, if one did exist.</i></p> <p><i>An article's methods section may provide information on the sample size needed to detect a hypothesized difference in outcomes and a discussion on statistical power (such as, the study had 85% power to detect a 20% increase in the rate of an outcome of interest, with a 2-sided alpha of 0.05). Sometimes estimates of variance and/or estimates of effect sizes are given, instead of sample size calculations. In any case, if the reviewers determined that the power was sufficient to detect the effects of interest, then they would answer 'yes' to Q5. A 'yes' would indicate 'good' quality.</i></p>			
<p><b><u>Bias in measurement of interventions</u></b>  <b><i>Was the test/service/intervention clearly described and delivered consistently across the study population?</i></b></p> <p>Was the intervention clearly defined in detail in the study? Did the authors indicate that the intervention was consistently applied to the subjects? Did the research participants have a high level of adherence to the requirements of the intervention?</p> <p><i>Reviewers ascertained that changes in study outcomes could be attributed to study interventions. If participants received interventions that were not part of the study protocol and could affect the outcomes being assessed, the results could be biased. A 'yes' would indicate 'good' quality but in this case it may be that the answer is more often less clearly stated due to the nature of the intervention.</i></p>			
<p><b><u>Bias in measurement of outcomes</u></b>  <b><i>Were the outcome measures pre-specified, clearly defined, valid, reliable, and assessed consistently across all study participants?</i></b></p> <p>Were the outcomes defined in detail? Were the tools or methods for measuring outcomes accurate and reliable-for example, have they been validated or are they objective? Check for use of validated measures and specific measures. If specific liver related measures are used this will help the quality rating of the study. A 'yes' would indicate 'good' quality.</p> <p><b><i>Were the generic Quality of Life outcome measures used complimented with Disease Specific Measures?</i></b></p> <p>There is some suggestion that generic and disease specific instruments may measure different HRQOL constructs and that generic and disease specific instruments should be complementary. A 'yes' would indicate a better quality study. However use of disease specific measure is not essential for a 'good' quality study.</p> <p><b><i>Were the people assessing the outcomes blinded to the participants' exposures/interventions?</i></b></p> <p>Blinding or masking requires that the outcome assessors do not know whether the participants received the intervention or were exposed to the factor under study. A 'yes' would indicate 'good' quality, although more than likely this will not be stated.</p> <p><b><i>Were outcome measures of interest taken multiples times before the</i></b></p>			

<p><b><i>intervention and multiple times after the intervention (ie did they use an interrupted time-series design)?</i></b></p> <p>Were the outcome measures for each person measured more than once during the course of the before and after study periods? Multiple measurements with the same result increase confidence that the outcomes were accurately measured. A 'yes' would indicate 'good' quality.</p>			
<p><b><u>Bias due to missing data</u></b></p> <p><b><i>Was the loss to follow up after baseline 20% or less? Were those lost to follow-up accounted for in the analysis?</i></b></p> <p>Higher overall follow up rates are always desirable to lower follow up rates, although higher rates are expected in shorter studies, and lower overall follow up rates are often seen in longer studies. Usually an acceptable overall follow up rate is considered 80% or more of participants whose interventions or exposures were measured at baseline. However, this is a general guideline.</p> <p><b><i>Were appropriate statistical methods used to account for missing data?</i></b></p> <p>In accounting for those lost to follow-up, in the analysis, investigators may have imputed values of the outcome for those lost to follow up or used other methods. For example, they may carry forward the baseline value or the last observed value of the outcome measure and use these as imputed values for the final outcome measure for research participants lost to follow up. A 'yes' would indicate 'good' quality.</p>			
<p><b><u>Bias in selection of the reported results</u></b></p> <p><b><i>Did the statistical methods examine changes in outcome measures from before to after the intervention? Were statistical tests done that provided p values for the pre-to-post changes?</i></b></p> <p>Were formal statistical tests used to assess the significance of the changes in the outcome measures between the before and after time periods? The reported study results should present values for statistical tests, such as p values, to document the statistical significance (or lack thereof) for the changes in the outcome measures found in the study. A 'yes' would indicate 'good' quality.</p> <p><b><i>Is the reported effect estimate unlikely to be selected, on the basis of the results, from multiple outcome measurements within the outcome domain or multiple analyses of the intervention-outcome relationship or selective reporting of a subset of the participants?</i></b></p> <p>Use of multiple measurement instruments (e.g. pain scales) and reporting only the most favourable result; the most favourable subscale (or a subset of subscales) for an instrument when measurements for other subscales were available; only one or a subset of time points for which the outcome was measured will bias the results from multiple outcome measures.</p> <p>Selective analysis reporting occurs when results are selected from intervention effects estimated in multiple ways e.g. carrying out analyses of both change scores and post-intervention scores adjusted for baseline; multiple analyses of a particular measurement with and without transformation; multiple analyses of a particular measurement with and without adjustment for potential confounders (or with adjustment for different sets of potential confounders); multiple analyses of a particular measurement with</p>			



<p>and without, or with different, methods to take account of missing data; a continuously scaled outcome converted to categorical data with different cut-points; multiple composite outcomes analysed for one outcome domain, but results were reported only for one (or a subset) of the composite outcomes. (Reporting an effect estimate for an unusual composite outcome might be evidence of such selective reporting.)</p> <p>Selection of a subgroup from a larger cohort occurs when the cohort for analysis may have been selected from a larger cohort for which data were available on the basis of a more interesting finding.</p> <p>Subgroups defined in unusual ways (e.g. an unusual classification of subgroups by dose or dose frequency) may provide evidence of such selective reporting.</p>			
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\*CD=cannot determine; NA= Not Applicable; NR=Not Reported

Higher numbers of 'yes' indicate higher quality study, unless the reviewer can state otherwise. Review each study as a unique in its own right for fair review of the design, methodology and reporting.

<b>Quality Rating (Good, Fair, or Poor) (see guidance)</b>
Rater #1 initials:
Rater #2 initials:
Additional Comments (Please state reasons for decision of Good/Fair/Poor):

**Quality Assessment Checklist. Adapted from NIH (National Heart, Lung, and Blood Institute) website for *Case Controlled Studies***

**Case-control study definition (from <http://childhoodcancer.cochrane.org/non-randomised-controlled-study-nrs-designs>)**

A study that compares people with a specific outcome of interest ('cases') with people from the same source population but without that outcome ('controls'), to examine the association between the outcome and prior exposure (e.g. having an intervention). This design is particularly useful when the outcome is rare.

Criteria	Yes	No	Other (CD,NR, NA)*
<p><b><u>Specifications of study Goals and Objectives</u></b>  <b><i>Was the study question or objective clearly and appropriately stated?</i></b>            Did the authors describe their goal in conducting this research? Is it easy to understand what they were looking to find?  <i>This issue is important for any scientific paper of any type. Higher quality research explicitly defines a research question. A 'yes' would indicate 'good' quality.</i></p>			
<p><b><u>Bias in selection of participants into the study</u></b>  <b><i>Was the study population clearly specified and defined?</i></b>            Did the authors describe the group of individuals from which the cases and controls were selected or recruited, while using demographics, location, and the time period? If the investigators conducted this study again, would they know exactly who to recruit, from where, and from what time period?  <i>Investigators identify case-control study populations by location, time period, and inclusion criteria for cases (individuals with the disease, condition, or problem) and controls (individuals without the disease, condition, or problem). A 'yes' would indicate 'good' quality.</i></p> <p><b><i>Were controls selected or recruited from the same or similar population that gave rise to the cases (including the same time frame)?</i></b>            To determine whether cases and controls were recruited from the same population, one can ask hypothetically, "If a control was to develop the outcome of interest (the condition that was used to select cases), would that person have been eligible to become a case?"            If the controls were recruited or selected from different populations, the answer to this question would be "no" and therefore of lesser quality because the populations are less comparable.</p> <p><b><i>Were the definitions, inclusion and exclusion criteria, algorithms or processes used to identify or select cases and controls valid, reliable, and implemented consistently across all study participants?</i></b>            Were the inclusion and exclusion criteria developed prior to recruitment or selection of the study population? Were the same underlying criteria used for all the groups involved?            The investigators should have used the same selection criteria, except for study participants who had the disease or condition, which would be different for cases and controls by definition. Therefore, the investigators use the same age (or age range), gender, race, and other characteristics to select cases and controls. Information on this topic is usually found in a paper's section on the</p>			

<p>description of the study population. A 'yes' would indicate 'good' quality.</p> <p><b>Were the cases clearly defined and differentiated from controls?</b>  Look for descriptions of the validity of case and control definitions and processes or tools used to identify study participants as such. Was a specific description of "case" and "control" provided? Is there a discussion of the validity of the case and control definitions and the processes or tools used to identify study participants as such? They determined if the tools or methods were accurate, reliable, and objective.</p> <p><b>Was there use of concurrent controls?</b>  A concurrent control is a control selected at the time another person became a case, usually on the same day. This means that one or more controls are recruited or selected from the population without the outcome of interest at the time a case is diagnosed. Investigators can use this method in both prospective case-control studies and retrospective case-control studies. For example, in a retrospective study of adenocarcinoma of the colon using data from hospital records, if hospital records indicate that Person A was diagnosed with adenocarcinoma of the colon on June 22, 2002, then investigators would select one or more controls from the population of patients without adenocarcinoma of the colon on that same day. This assumes they conducted the study retrospectively, using data from hospital records. The investigators could have also conducted this study using patient records from a cohort study, in which case it would be a nested case-control study.  <i>Investigators can use concurrent controls in the presence or absence of matching and vice versa. A study that uses matching does not necessarily mean that concurrent controls were used.</i></p> <p><b>Were the investigators able to confirm that the exposure/risk occurred prior to the development of the condition or event that defined a participant as a case?</b>  Investigators first determine case or control status (based on presence or absence of outcome of interest), and then assess exposure history of the case or control; therefore, reviewers ascertained that the exposure preceded the outcome. For example, if the investigators used tissue samples to determine exposure, did they collect them from patients prior to their diagnosis? If hospital records were used, did investigators verify that the date a patient was exposed (e.g., received medication for atherosclerosis) occurred prior to the date they became a case (e.g., was diagnosed with type 2 diabetes)? For an association between an exposure and an outcome to be considered causal, the exposure must have occurred prior to the outcome.</p>			
<p><b><u>Bias in limited sample size</u></b>  <b>Did the authors include a sample size justification?</b>  Did the authors discuss their reasons for selecting or recruiting the number of individuals included? Did they discuss the statistical power of the study and provide a sample size calculation to ensure that the study is adequately powered to detect an association (if one exists)? Was the sample size justification adequate? This question does not refer to a description of the manner in which different groups were included or excluded using the inclusion/exclusion criteria. A 'yes' would indicate 'good' quality.</p>			

<p><b><u>Bias in measurement of interventions</u></b>  <b><i>Were the measures of intervention clearly defined, valid, reliable, and implemented consistently (including the same time period) across all study participants?</i></b></p> <p>Were the intervention measures defined in detail? Were the tools or methods used to measure accurate and reliable—for example, have they been validated or are they objective? This is important, as it influences confidence in the reported exposures. Equally important is whether the intervention was assessed in the same manner within groups and between groups. This question pertains to bias resulting from exposure misclassification (i.e., exposure ascertainment). For example, a retrospective self-report of dietary salt intake is not as valid and reliable as prospectively using a standardized dietary log plus testing participants' urine for sodium content because participants' retrospective recall of dietary salt intake may be inaccurate and result in misclassification of exposure status. Similarly, BP results from practices that use an established protocol for measuring BP would be considered more valid and reliable than results from practices that did not use standard protocols. A protocol may include using trained BP assessors, standardized equipment (e.g., the same BP device which has been tested and calibrated), and a standardized procedure (e.g., patient is seated for 5 minutes with feet flat on the floor, BP is taken twice in each arm, and all four measurements are averaged). <i>A 'yes' would indicate 'good' quality.</i></p> <p><b><i>Were the generic Quality of Life outcome measures used complimented with Disease Specific Measures?</i></b></p> <p>There is some suggestion that generic and disease specific instruments may measure different HRQOL constructs and that generic and disease specific instruments should be complementary. <i>A 'yes' would indicate a better quality study. However use of disease specific measure is not essential for a 'good' quality study.</i></p> <p><b><i>Were outcome measures of interest taken multiples times before the intervention and multiple times after the intervention (ie did they use an interrupted time-series design)?</i></b></p> <p>Were the outcome measures for each person measured more than once during the course of the before and after study periods? Multiple measurements with the same result increase confidence that the outcomes were accurately measured. <i>A 'yes' would indicate 'good' quality.</i></p> <p><b><i>Were key potential confounding variables measured and adjusted statistically in the analyses? If matching was used, did the investigators account for matching during study analysis?</i></b></p> <p>Were key potential confounding variables measured and adjusted for, such as by statistical adjustment for baseline differences? Investigators often use logistic regression or other regression methods to account for the influence of variables not of interest. This is a key issue in case-controlled studies; statistical analyses need to control for potential confounders, in contrast to RCTs in which the randomization process controls for potential confounders. In the analysis, investigators need to control for all key factors that may be associated with both the exposure of interest and the</p>			
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<p>outcome and are not of interest to the research question.</p> <p>A study of the relationship between smoking and CVD events illustrates this point. Such a study needs to control for age, gender, and body weight; all are associated with smoking and CVD events. Well-done case-control studies control for multiple potential confounders.</p> <p><i>Matching is a technique used to improve study efficiency and control for known confounders. For example, in the study of smoking and CVD events, an investigator might identify cases that have had a heart attack or stroke and then select controls of similar age, gender, and body weight to the cases. For case-control studies, it is important that if matching was performed during the selection or recruitment process, the variables used as matching criteria (e.g., age, gender, race) should be controlled for in the analysis.</i></p>			
<p><b>Bias in measurement of outcomes</b></p> <p><b><i>Were the outcome measures pre-specified, clearly defined, valid, reliable, and assessed consistently across all study participants?</i></b></p> <p>Were the outcomes defined in detail? Were the tools or methods for measuring outcomes accurate and reliable-for example, have they been validated or are they objective? Check for use of validated measures and specific measures. If specific liver related measures are used this will help the quality rating of the study. A 'yes' would indicate 'good' quality.</p> <p><b><i>Were the generic Quality of Life outcome measures used complimented with Disease Specific Measures?</i></b></p> <p>There is some suggestion that generic and disease specific instruments may measure different HRQOL constructs and that generic and disease specific instruments should be complementary. A 'yes' would indicate a better quality study. However use of disease specific measure is not essential for a 'good' quality study.</p> <p><b><i>Were the people assessing the outcomes blinded to the participants' exposures/interventions?</i></b></p> <p>Blinding or masking requires that the outcome assessors do not know whether the participants received the intervention or were exposed to the factor under study. A 'yes' would indicate 'good' quality, although more than likely this will not be stated.</p> <p><b><i>Were outcome measures of interest taken multiples times?</i></b></p> <p>Were the outcome measures for each person measured more than once during the course of the study? Multiple measurements with the same result increase confidence that the outcomes were accurately measured. A 'yes' would indicate 'good' quality.</p>			

<p><b>Bias due to missing data</b>  <b>Was the loss to follow up after baseline 20% or less? Were those lost to follow-up accounted for in the analysis?</b>  Higher overall follow up rates are always desirable to lower follow up rates, although higher rates are expected in shorter studies, and lower overall follow up rates are often seen in longer studies.  <i>Usually an acceptable overall follow up rate is considered 80% or more of participants whose interventions or exposures were measured at baseline. However, this is a general guideline.</i>  <b>Were appropriate statistical methods used to account for missing data?</b>  <i>In accounting for those lost to follow-up, in the analysis, investigators may have imputed values of the outcome for those lost to follow up or used other methods. For example, they may carry forward the baseline value or the last observed value of the outcome measure and use these as imputed values for the final outcome measure for research participants lost to follow up. A 'yes' would indicate 'good' quality.</i></p>			
<p><b>Bias in selection of the reported results</b>  <b>Did the statistical methods examine changes in outcome measures from before to after the intervention? Were statistical tests done that provided p values for the pre-to-post changes?</b>  Were formal statistical tests used to assess the significance of the changes in the outcome measures between the before and after time periods? The reported study results should present values for statistical tests, such as p values, to document the statistical significance (or lack thereof) for the changes in the outcome measures found in the study. A 'yes' would indicate 'good' quality.  <b>Is the reported effect estimate unlikely to be selected, on the basis of the results, from multiple outcome measurements within the outcome domain or multiple analyses of the intervention-outcome relationship or selective reporting of a subset of the participants?</b>  Use of multiple measurement instruments (e.g. pain scales) and reporting only the most favourable result; the most favourable subscale (or a subset of subscales) for an instrument when measurements for other subscales were available; only one or a subset of time points for which the outcome was measured will bias the results from multiple outcome measures.  <b>Selective analysis reporting</b> occurs when results are selected from intervention effects estimated in multiple ways e.g. carrying out analyses of both change scores and post-intervention scores adjusted for baseline; multiple analyses of a particular measurement with and without transformation; multiple analyses of a particular measurement with and without adjustment for potential confounders (or with adjustment for different sets of potential confounders); multiple analyses of a particular measurement with and without, or with different, methods to take account of missing data; a continuously scaled outcome converted to categorical data with different cut-points; multiple composite outcomes analysed for one outcome domain, but results were reported only for one (or a subset) of the composite outcomes. (Reporting an effect estimate for an unusual composite outcome might be evidence of such selective reporting.)  <b>Selection of a subgroup from a larger cohort occurs when</b> the cohort for analysis may have been selected from a larger cohort for which data were available on the basis of a more interesting finding.</p>			

Subgroups defined in unusual ways (e.g. an unusual classification of subgroups by dose or dose frequency) may provide evidence of such selective reporting.			
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<b>Quality Rating (Good, Fair, or Poor) (see guidance)</b>
Rater #1 initials:
Rater #2 initials:
Additional Comments (If Poor, Please state why):